HELP-SEEKING FOR POTENTIAL SYMPTOMS OF GYNAECOLOGICAL CANCER AMONGST OBESE WOMEN: A MIXED METHODS STUDY

by

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ABSTRACT

Obesity has been associated with an increased risk of developing some gynaecological cancers, and with delayed help-seeking. The thesis aims were to identify factors predictive of extended (i.e. ‘delayed’) time to help-seeking for women seeking help for potential symptoms of gynaecological cancers, particularly looking at the role of obesity on time to help-seeking. Qualitative and exploratory research further investigated health beliefs and help-seeking attitudes of women experiencing gynaecological cancer symptoms and built a framework for understanding women’s complex journeys toward medical help-seeking. Additionally, the research assessed for differences in time to help-seeking and cancer awareness across groups with varying body mass indexes (BMIs) and different ethnic groups. Findings suggested that women have a limited awareness of gynaecological cancers, nevertheless, low awareness of gynaecological cancers was *not* associated with help-seeking delay. Thesis studies showed that obese women were *not* more likely to delay help-seeking when compared to non-obese women, and that attendance at preventative screenings *was* a predictor of delayed help-seeking. In conclusion the thesis provided an understanding of the often-complex transition through the menopause and challenged assumptions in the literature about the association between obesity, help-seeking and preventative screenings. Future research should further explore the complex relationship between BMI and help-seeking for gynaecological cancer symptoms.

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I'd like to dedicate this thesis to the loving memory of my parents,

Margarita and Paul Tookey.

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LIST OF ABBREVIATIONS

BMI	Body mass index
CDCP	Centre for Disease Control and Prevention
CIN	Cervical intraepithelial neoplasia
CSM/SRM	Common Sense Model/Self-Regulation Model
GP	General Practitioner
HCP	Healthcare professional/ Healthcare provider
HPV	Human papillomavirus
HRC	Hormone replacement therapy
NICE	National Institute for Clinical Excellence
PMB	Post-menopausal bleeding
SES	Socioeconomic status
STI	Sexually transmitted infection
VAIN	Vaginal intraepithelial neoplasia
VIN	Vulval intraepithelial neoplasia
WHO	World Health Organisation

STATEMENT OF AUTHORSHIP

Chapters 4 to 7 contain material that have been submitted or prepared for publication to academic journals. Therefore, each chapter has been presented with an introduction and discussion. Although effort has been made to avoid repetition where possible, there may be overlapping of material given that three studies were conducted using the identical sample. The authorship on each chapter indicates collaborative working with my supervisors Michael Larkin, Elizabeth Grunfeld and Ruth Howard of whom provided feedback on earlier drafts of each study and chapter in this thesis. Nevertheless, I collected and analysed the data in all of the chapters and I am the primary author. Chapter 4 was submitted to an academic journal and included collaborative working in earlier drafts from Gynaecological Oncologist, Sean Kehoe who provided expert feedback on the topic area of PMB and gynaecological cancers. Colleague, Lailah Alidu provided an inter-rater review of themes derived from the framework analysis conducted in the Chapter 4 study.

THESIS OVERVIEW

Chapter 1 provides a clinical overview of gynaecological cancers, related symptoms, epidemiology, causes and risk factors, diagnostic pathways, treatments and outcomes. Chapter 2 provides a review of symptom perception and help-seeking behaviour theories and models to identify theories that inform the thesis research. Chapter 3 provides a summary of the aims and the research plan for the following empirical chapters. Chapter 4 presents results of a qualitative study that explored healthcare professionals' perspectives about the potential barriers, beliefs and behaviours of the obese women seeking help for symptoms of gynaecological cancer from their services. Results highlighted that healthcare professionals perceived that obese women have a poor understanding of the risks and symptoms of gynaecological cancers and that women experience obesity as both a physical and emotional barrier to medical help-seeking for potential symptoms of gynaecological cancers. Therefore healthcare professionals suggested that intervention and healthcare provisions may be needed to encourage obese women to seek help sooner and that healthcare services should be adapted to accommodate the specific needs of obese women.

Chapter 5 used a multiple regression analysis to identify predictors of delayed help-seeking for symptoms of gynaecological cancer. The results identified that increased body mass index, living in a neighbourhood perceived by participants as high in crime and, interestingly, an individual's participation in regular preventative health behaviours (e.g. attendance at cervical and breast screenings) were predicted to extend time to help-seeking.

Chapter 6 presents an additional analysis that mapped the dynamic process of help-seeking and associated behaviours involved in seeking medical help for PMB, and compared differences in help-seeking and gynaecological cancer awareness across different groups of obese and non-obese women and different ethnic groups (White European and Black, Asian and minority ethnic groups). No differences were found across groups regarding time to help-seeking and gynaecological awareness. Furthermore, gynaecological cancer was not associated with time to help-seeking. The results of Chapter 6 provided an interesting and comprehensive view of the journey to help-seeking, including the presence of concerns prior to seeking help, women's participation in self-management behaviours, and successful alternative routes to care (i.e. non-GP methods of help-seeking). Furthermore this study presented contradictory findings regarding the relationship between BMI and time to help-seeking, suggesting that the two may exist in a curvilinear relationship.

Chapter 7 details a qualitative study that explored the experiences and beliefs of seven obese women in their journey toward help-seeking for PMB, and identifies how women make sense of these experiences. Results of this study identified three superordinate themes to describe this complex experience and included the ambiguous nature of PMB and the menopausal experience that enmeshed the two experiences together in the context of aging, an experience of the body as chaotic and the perception of the PMB investigation as a necessary intrusion.

Chapter 8 provides a general discussion relating back to the literature, discusses the research limitations, suggest directions for future research and intervention, and outlines the theoretical and practical implications of the present research to formulate an overall conclusion for the PhD.

CHAPTER 1: GYNAECOLOGICAL CANCER- A CLINICAL REVIEW

Overview

Gynaecological cancers encompass a varied group of site-specific tumours located within the female reproductive system (Figure 1.1), and account for just under a quarter of all diseases in women according to the most recent UK statistical reports of incidence in 2011 (Cancer Research UK, 2014a). This chapter provides the clinical information necessary to build a knowledge base for gynaecological cancer research in the UK and outlines incidence and mortality rates for gynaecological cancers, risk factors, signs and symptoms, treatments and outcomes to enable understanding of the burden of the disease, and to identify factors associated with help-seeking behaviours and survival outcomes.

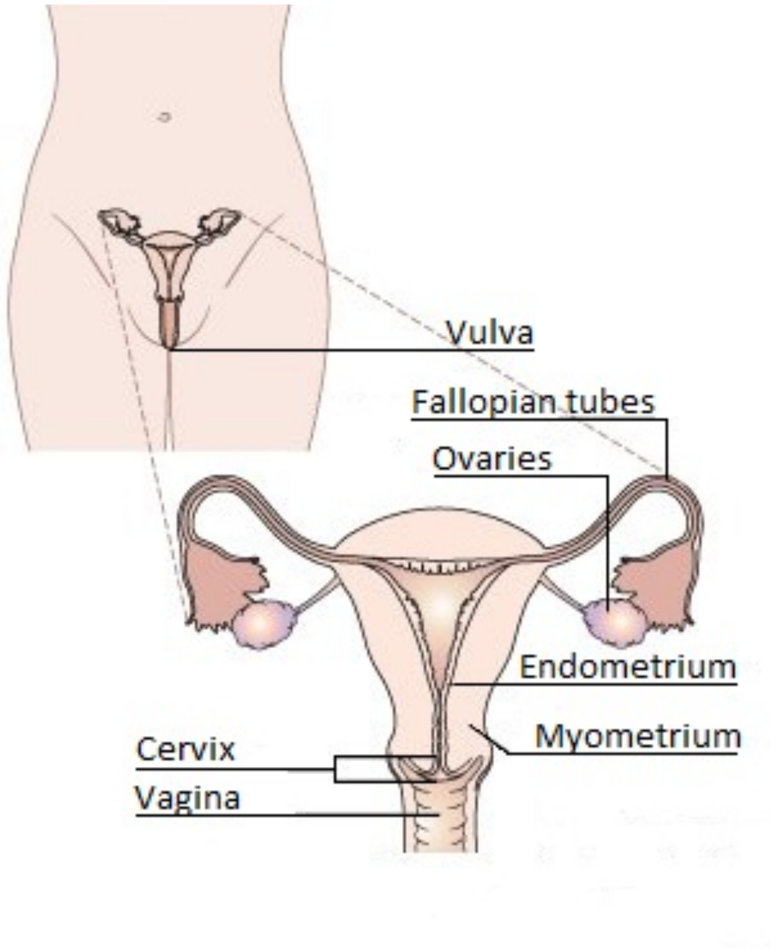

Figure 1.1. Female reproductive organs diagram. Adapted from Cancer Research UK (2013a) with permission for public use.

Gynaecological cancers include: (a) endometrial cancer (i.e. cancer of the womb, endometrium or uterus), (b) cervical cancer (i.e. cancer of the cervix uteri or the neck of the womb), (c) ovarian cancer (i.e. cancer of the ovaries, which may include fallopian tube cancers), (d) cancer of the vulva, and (e) cancer of the vagina.

Each site has distinct incidence and mortality rates, causes and risk factors, signs and symptoms, diagnostic pathways, treatments and survival rates (US Department of Health and Human Services, 2012). All gynaecological cancers are defined by the presence of a *primary* malignant tumour or cancerous cells that originate in a specific area of the body. Spreading occurs when malignant cells break away from the primary tumour and move through the blood stream and lymphatic system (Figure 1.2.) to reach a new area, often dividing to form new tumours known as *secondary cancers* or *metastases* (Shayan, Achen, Stacker& 2006; Cancer Research UK, 2013b). As with all cancers, morbidity is determined by the site-specific stage of disease, which describes the extent of cancerous spread throughout the body.

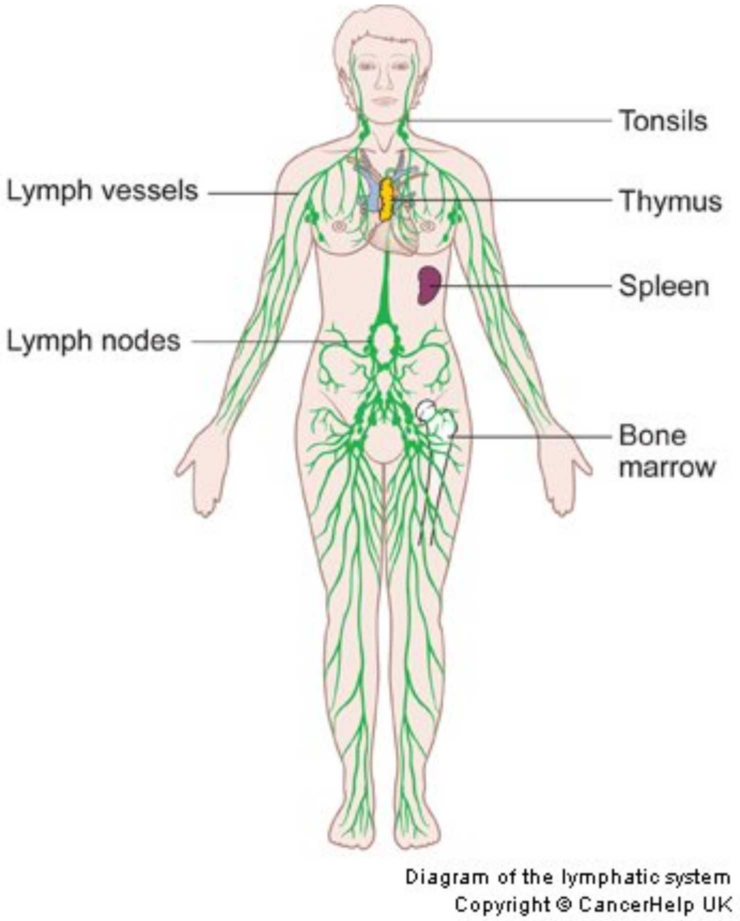

Figure 1.2. Lymphatic system diagram**.** Retrieved with public use permission from Cancer Research UK (2013b).

Cervical cancer affects an area in the lower part of the uterus, often called the neck of the womb. Cancer of the vulva is an uncommon cancer of the entrance of the vagina (Figure 1.3.). Cancer of the vagina is the most rare of all gynaecological cancers, affecting the vaginal canal. Cancer of the ovaries commonly affects the outer surface layer of the ovary (i.e. epithelial ovarian cancer), and can also originate within the cells that produce the eggs or ova (i.e. germ cell tumours) or within the structural tissue cells that hold the ovaries together (i.e. stromal tumours; American Cancer Society, 2014a). Endometrial cancer (i.e. womb or uterine cancer) is the most common of all gynaecological cancers, and is defined by cancer in the lining of the uterus (i.e. the endometrium; Cancer Research UK, 2014a). The uterus is a muscular, pear-shaped organ at the top of the vagina. Cancer that begins in the muscle layers of the uterus rather than the lining is categorised as uterine sarcoma.

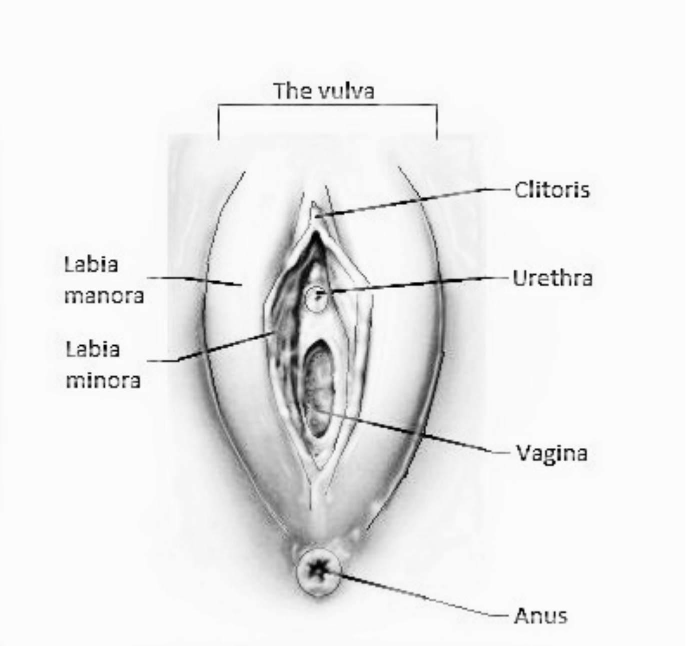

Figure 1.3. Diagram of the vulva: Outer part of female genitalia. Retrieved with public use permission from Mayo Foundation for Medical Education & Research (2014).

Incidence and Mortality

Gynaecological cancers have the second highest incidence of any female cancer in the UK, behind breast cancer and ahead of colorectal and lung cancer (Cancer Research UK, 2014a). Cervical cancer is globally the fourth most common cancer amongst women, with the highest incidence reported in developing countries (Ferlay et al., 2013a), and endometrial cancer is the sixth most common cancer, with the highest incidence rate reported in *developed* countries (Ferlay et al., 2013b). Ovarian cancer is globally the seventh most prevalent cancer amongst women (Ferlay et al., 2013a). Cancers of the vagina and vulva account for less than 7% of all reported diagnoses of gynaecological cancers (Cancer Research UK, 2014a). Recent reports suggest that endometrial cancer is the most common of all gynaecological cancers diagnosed in the UK, and that ovarian cancer has the highest morbidity (Cancer Research UK, 2014a). The Cancer Research UK (2014a) report presents the number of gynaecological cancer cases diagnosed in the UK from most prevalent to least: (a) endometrial cancer, $n = 8475$; (b) ovarian, $n = 7116$; cervical, $n = 3064$; vulva, $n = 1203$; vaginal, $n = 256$. Mortality rates for the disease are dependent upon the stage at time of diagnosis, with early diagnosis greatly increasing chance for survival (Memon, 2009).

Many gynaecological cancers affect women of post-menopausal age (average post-menopausal age is 51; Sankaranarayanan & Ferlay, 2006). Conversely, cervical cancer often affects women of younger ages, and rates increase steadily until women reach 39 years of age when the incidence rates begin to reduce (Memon, 2009). Like most gynaecological cancers, endometrial cancer is rarely diagnosed before age 34 with approximately 73% of cases diagnosed between the ages of 40 and 75 (Howlader, et al., 2014) and incidence rates increase after age 40, reaching its highest incidence by the age of 64 (Memon, 2009).

Two out of every three women (67.4%) who are diagnosed with cervical cancer and 58% of women diagnosed with cancers of the vulva and vagina in the UK will survive at least five years after diagnosis (i.e. five-year relative survival rate) (Cancer Research UK, 2014b). Nevertheless, cancers of the vulva and vagina are rare and account for less than one per cent of all cancer deaths in women (Cancer Research UK, 2014a). The five-year survival rate for ovarian cancer is about 46%, if diagnosed while still in the early or localised stages this rises to over 80% (Cancer Research UK, 2014b). Mortality rates for ovarian cancer exceed that of other gynaecological cancers considerably, which is suggested to be due to late-stage presentation (i.e. cancer not diagnosed until in an advanced stage), indicated by 56% of cases presenting in emergency services (Public Health England, 2015). Late-stage presentation is suggested to be due to the non-specific or vague presentation of symptoms that often occurs in women (e.g. bloating, feeling full quickly; Goff, Mandel, Melancon, & Muntz, 2014). Endometrial cancer has a mortality rate accounting for three per cent of all cancer deaths, with a five-year survival rate of 79% (Cancer Research UK, 2014b). A steady increase in endometrial cancer incidence and morbidity may be associated with the growing prevalence of female obesity (Bray, dos Santos Silvia, Moller & Weiderpass, 2005; Calle & Kaaks, 2004), given that the literature reports a strong association with obesity and the development of endometrial cancer (Bhaskaran et al., 2014; Lane, 2008; Reeves et al., 2007; Stevens, Jacobs, Patel, Sun, Gapstur, & McCullough, 2014; World Cancer Research Fund/American Institute for Cancer Research, 2013). This is important, because endometrial cancer is reported to have the highest associated risk of all the “obesity-related” cancers (i.e. breast, colon, oesophageal, endometrial, ovarian, kidney and pancreas; Polednak, 2008).

Risk Factors

Common risk factors for gynaecological cancers include: (a) post-menopausal age (with the exception of cervical cancer; Calle, Kaaks, 2004); (b) genetic factors (i.e. family history of breast or colon cancer; Gayther & Pharoah, 2010); (c) hormonal imbalance of progesterone/oestrogen (commonly caused by hormone replacement therapy [HRT], breast cancer oestrogen treatments, infertility, late menopause or infrequent menstrual cycles; La Vecchia & Boccia, 2014; Tinelli, Vergara, Martignago, Leo, Malvasi & Tinelli, 2008); (d) sexually transmitted infection (Bosch, Lorincz, Muñoz, Meijer, & Shah, 2002; Grulich, van Leeuwen, Falster, & Vajdic, 2007); (e) obesity and comorbid disease (i.e. diabetes, hypertension; Bray et al., 2005; Starup-Linde et al., 2014; Memon, 2009); (f) lifestyle factors (e.g. smoking and poor diet; National Cancer Intelligence Network, 2014; Web, 2015; Parkin, Boyd, & Walker, 2011). See Table 1.1.

Genetic risk factors for ovarian and endometrial cancers include the BRCA1 gene (i.e. breast cancer gene; Gayther & Pharoah, 2010). Additionally, a family history of bowel cancer (i.e. HNPCC gene) or endometrial cancer increases the likelihood of developing endometrial cancer (Watson, Vasen, Mecklin, Jarvinen, & Lych, 1994). A primary risk factor for cancers of the cervix, vulva and vagina is the human papilloma virus (HPV; Bosch et al., 2002). HPV is a sexually transmitted infection and includes a group of viruses that affect cells lining the cervix. It is defined by abnormal tissue growth and pre-cancerous cellular changes on the cervix, which can also present as genital warts. HPV is present in nearly all cases of cervical cancer in the UK (Parkin, Boyd & Walker, 2011), and is the cause of pre-cancerous lesions in cervical cancer (i.e. CIN), vaginal cancer (i.e. VAIN) and cancer of the vulva (i.e. VIN) (Basta, Adamek, & Pitynski, 1999; Kumar, Abbas, Fausto, & Mitchel, 2007).

Hormonal exposure from oral contraceptives (in particular those containing progesterone) is a common risk factor for cervical cancer (La Vecchia & Boccia, 2014). Conversely, it is suggested that the use of oral contraceptives reduces the risk of developing endometrial and ovarian cancers (Havrileski, 2013; Salehi, Dunfield, Phillips, Krewski, &Vanderhyden, 2008) by increasing exposure to oestrogen, unopposed by progestins, which otherwise increases the risk of developing endometrial and ovarian cancers (Kaaks, Lukanova, & Kurzer, 2002; Sueblinvong & Carney, 2009), resulting in a thickened endometrium. This relationship between hormones and increased risk for developing gynaecological cancers is associated with the use of oestrogen-only HRT and hormonal treatments for breast cancer or infertility (infertility increasing the length of time women are exposed to oestrogen, which is low during periods of pregnancy; Pearce, Chung, Pike, & Wu, 2009; Jensen, Sharif, Olsen, & Kruger Kjaer, 2008).

The hormonal association is strongest in endometrial cancer, which is described as a hormonal carcinogenesis, identifying hormones (i.e. oestrogens and progestins) as the main factor in driving cell proliferation and growth of cancer cells (Tinelli et al., 2008). Other known hormonal-related cancers include breast, ovarian, testicular, thyroid and osteosarcoma (Henderson & Feigelson, 2000). Excess exposure to unopposed oestrogen affects the uterine tissue by stimulating a proliferation of cells (Lukanova et al., 2004; Pike, Pearce, & Wu, 2004), resulting in a thickened lining of the uterus (i.e. endometrium). Any prolonged exposure to oestrogen can increase the risk of developing endometrial cancer, as is the case with women who experience late menopause or early menarche (Pike et al., 2004) and obese women (Kaaks, Lukanova, & Kurver, 2002). Furthermore, once through the menopause all oestrogen becomes unopposed, resulting in an increased risk for the development of endometrial cancer (Calle & Kaaks, 2004).

Obesity as a Risk Factor

Obesity is defined by the World Health Organisation (WHO; 2000) in categories of body mass index (BMI), which measures weight and height and is defined as an individual's weight in kilograms divided by the square of his or her height in meters (kg/m^2). Individuals are categorised as overweight when their BMI measures at 25 or above, and obesity is measured at 30 or above. Obesity is a common risk factor in the development of some gynaecological cancers (e.g. ovarian and endometrial; Bhaskaran et al., 2014; Olsen et al., 2013; Reeves et al., 2007; Stevens et al., 2014; World Cancer Research Fund /American Institute for Cancer Research, 2013). The association with obesity and gynaecological cancer is reported to be due to the storage of oestrogen in body fat, which is significantly increased in obese individuals (Kaaks, Lukanova, & Kurver, 2002).

A recent meta-analysis suggests that the risk for developing endometrial cancer is higher in women with adulthood obesity, and this risk increases by 81% with the amount of weight gained during adulthood (relative risk of 1.81, 1.66 – 1.98 increase per 5 kg/m^2 BMI increase; Stevens et al., 2014), and an increase in cervical cancer at a relative risk of 1.1, 1.03 to 1.17 (Kmeitowicz, 2014). Findings of the ovarian cancer and obesity link are less clear, however findings suggest that obesity may increase the risk for developing low-grade serous invasive ovarian tumours by 13% for every 5 kg/m^2 increase in BMI (relevant risk 1.13, 1.03 – 1.25; Olsen et al., 2013), and mixed findings suggest that the use of HRT increases risk by up to 10% for every 5 kg/m^2 BMI increase (relevant risk 1.10, 1.07 – 1.03; Collaborative Group in Epidemiological Studies of Ovarian Cancer, 2012; Olsen et al., 2013). An opposite effect is found in endometrial cancers, suggesting that obesity is linked to a higher risk of developing endometrial cancer amongst those who have *never* used HRT (Crosbie, Zwahlen, Kitchener, Egger, & Renehan, 2010).

A report from World Cancer Research Fund/American Institute for Cancer Research (2013) suggests that obesity alone may account for four out of ten endometrial cancer diagnoses worldwide. Obesity can affect cancer growth by influencing the levels of hormones and growth factors in the body (Hursting, Lavigne, Berrigan, Perkins, & Barrett, 2003). Furthermore, abdominal fat increases insulin resistance, which causes the pancreas to compensate by increasing insulin production and promoting cancer cell growth, increasing the risk for colon, endometrial and pancreatic cancers (Calle & Kaaks, 2004). Adipose tissue (i.e. fat tissue) synthesises oestrogen for post-menopausal women (Calle & Kaaks, 2004) and increases the conversion of androgen to oestrogen (Westley & May, 2013). Additionally, unopposed oestrogen is associated with a low-grade chronic inflammatory state, and promotes inflammation of uterine tissue (Hale, Hughes & Cline, 2002), which enables tumour cell proliferation and cancer growth (Rexrode et al., 2003). The hormonal influences facilitate thickening of the endometrium, subsequently increasing morbidity from gynaecological cancers, such as endometrial cancer (Calle & Kaaks, 2004).

Obesity and obesity-related diseases (i.e. diabetes and hypertension) are suggested to increase the risk factors of cervical, ovarian and endometrial cancers (Memon, 2009; Starup-Linde et al., 2014), however, this relationship may be partially related to overweight and obese women's reduced attendance in cervical screening programmes (Maruthur, Bolen, Brancati, & Clark, 2009), and increased diagnoses of polycystic ovary syndrome (i.e. Stein-Leventhal Syndrome) or endometrial hyperplasia (Hardiman, Plillay, & Atiomo, 2003). Diagnoses of endometriosis (i.e. a condition of uterine lining growth beyond the uterus) or ovarian cysts are additional risk factors for ovarian cancer that can affect obese populations (Borgfeldt & Andolf, 2004; Kim, Kim, Chung, & Song, 2014). Furthermore, obesity and diabetes have been associated with symptoms of post-menopausal bleeding (PMB) and the development of endometrial cancer. Obese women are 19%, and diabetic women are 21% more likely to experience PMB than women without these risk factors (Breijer, Timmermans, Doorn, Mol, & Opmeer, 2010).

There are inconsistent findings to suggest that lifestyle factors may increase the risk for gynaecological cancers (e.g. sedentary lifestyle, smoking, eating a diet high in lactose and saturated fat; Braaten, Weiderpass, & Lund, 2009; Memon, 2009; Web, 2015). Incidence is associated with socio-economic deprivation amongst cancers of the vulva, vagina and cervix, however, incidence rates of endometrial and ovarian cancer are reported slightly higher amongst more affluent groups than the more deprived (National Cancer Intelligence Network, 2014). Findings suggest that a low socioeconomic status may be associated with a general reduction in cancer survival (National Cancer Intelligence Network, 2014) and may be due in part to an increase in smoking habits and poor diet amongst lower educated populations, this increases the likelihood of developing comorbid diseases, further increasing cancer mortality (Braaten, Weiderpass, & Lund, 2009). An American study showed that socioeconomic status was a greater independent predictor of endometrial cancer survival than race or ethnicity, and that both higher income and hysterectomy surgery were associated with increased survival rates (Madison, Schottenfeld, James, Schwartz, & Gruber, 2004).

Review of the literature highlights obesity as a key risk factor for the development of gynaecological cancers and reduced attendance at regular preventative screenings (Maruthur et al., 2009; Phelan, Burgess, Yeazel, Hellerstedt, Griffin, & van Ryn, 2015; Puhl & Brownell, 2006; Puhl & Heuer, 2009), thereby increasing the likelihood of morbidity amongst obese women diagnosed with gynaecological cancers.

Protective Factors

There are a number of factors that protect against the likelihood of developing gynaecological cancers. Those most commonly reported are: The use of oral contraceptives with progesterone, hysterectomy, multiple pregnancies (i.e. periods of time with low exposure to oestrogen and increased progesterone) and HPV prevention behaviours (i.e. vaccination, condom use, abstaining from sex; Bosch & Harper, 2006; Muñoz et al., 2010; Winer et al., 2006). A strong relationship has been found between a reduction in the risk for ovarian cancer and oral contraceptive use with hysterectomy surgery (25 - 28% risk-reduction), and oral contraceptive use suggested to reduce the risk by up to 50% with ten or more years of regular use (retrieved from Havrilesky et al., 2013). Being pregnant more than once may reduce the risk of ovarian and endometrial cancers by up to 55%, further reducing risk with each additional birth (Havrilesky et al., 2013). Additionally, HPV prevention behaviours, implantation of an intrauterine device and an increased intake in Vitamin A have all been suggested to reduce the risk for cervical cancer (Castellsague et al., 2011; Zhang, Dai, Zhang, & Wang, 2012). Inconclusive evidence suggests that a diet high in cruciferous vegetables (e.g. broccoli, kale, cauliflower, Brussels sprouts, cabbage) and low in dairy and animal fat may reduce the risk for ovarian cancer (Bosetti et al., 2012; Memon, 2009). Furthermore, physical activity may reduce the risk of endometrial and ovarian cancers by up to 20% (Cust, 2011). See Table 1.1.

Signs and Symptoms

Signs and symptoms for gynaecological cancers vary by site. Signs are defined as biologically based and are objective bodily sensations (Scott, 2010). From the acknowledgment of these biological signs comes the recognition of symptoms, where symptoms are defined as the subjective experience of a physiological change (Scott, 2010). Symptoms are only experienced by the affected person and are often unknown to others until the experience is communicated (Pennebaker & Brittingham, 1982). Understanding the signs and symptoms of gynaecological cancers is essential in conceptualising the psychological factors that may lead an individual to seek help. Individuals are more likely to seek help for severe or salient symptoms (i.e. symptoms that interfere with daily life), however the non-specific and often vague symptoms of gynaecological cancers may increase delay for gynaecological cancer symptoms (Evans, Ziebland, & McPherson, 2007). See Table 1.1 for a summary overview of the incidence, risk factors, protective factors and symptoms of gynaecological cancers.

Table 1.1.

Gynaecological Cancers in the UK: A Summary Table

Cancer type	Incidence	Risk Factors	Protective Factors	Symptoms
Cervical	*n* = 3064	Family history. HPV. Oral contraceptives (w/progesterone). Obesity. Low SES.	Cervical Screening. Intrauterine device. Protected sex or abstinence.	Abnormal vaginal bleeding (post-coital, between periods, post-menopausal) or abnormal discharge.
Vulva	*n* = 1203	Post-menopausal age. Family history. HPV. Low SES.	Cervical Screening. Protected sex or abstinence.	Persistent itching, burning or pain of the vulva. Persistent rash, ulcer or lump on the vulva. Changes on the colour or texture of the vulva skin.
Vaginal	*n* = 256	Post-menopausal age. Genetic factors. HPV. Low SES.	Cervical Screening. Protected sex or abstinence.	Abnormal vaginal bleeding (post-coital, between periods, post-menopausal) or abnormal discharge. Urination urgency and increased frequency. Vaginal pain during sexual intercourse.
Ovarian	*n* = 7116	Post-menopausal age. Genetic factors: BRCA1. Obesity. HRT.	Oral contraceptives (w/progesterone). Hysterectomy. Multiple pregnancies. Physical activity.	Pelvic or abdominal pain or pressure. Bloating. Urination urgency and increased frequency. Increased abdominal size. Abnormal bowel habits.
Endometrial	*n* = 8475	Post-menopausal age. Genetic factors: BCRCA1 & HNPCC & family history of endometrial cancer Obesity & diabetes.	Oral contraceptives (w/progesterone). Hysterectomy. Multiple pregnancies. Physical activity.	Abnormal vaginal bleeding (between periods, post-menopausal).

Adapted from Centers for Disease Control and Prevention (2014) and Cooper, Polonec, Stewart, & Gelb (2013).

Cancers of the cervix, vulva and vagina can take years to develop and usually first present at healthcare services in the early stages (i.e. pre-cancerous cells). Early stages of cervical cancer (pre-cancerous or pre-invasive carcinoma) are commonly asymptomatic and are often detected during regular cervical screening tests. However, when abnormal cells become cancerous (i.e. invasive carcinoma) symptoms include abnormal vaginal bleeding or discharge, and some women may experience discomfort or pain during sex (National Institute for Care and Health Excellence [NICE], 2005; Center for Disease Control and Prevention [CDCP], 2014).

Common symptoms of cancer of the vulva include persistent pain, burning or itching of the vulva, ulcers, lumps or wart-like growths on the vulva, or a mole that changes shape or colour over time (CDCP, 2014). Symptoms for cancer of the vulva can affect the labia majora, labia minora, and the clitoris (Souhami & Tobias, 2003). Most women who experience symptoms of cancer of the vulva are unaware of their association with cancer and often choose to seek medical help only once symptoms increase in salience, for the development of an ulcer with pain, or an affected lymph node on the groin that has persisted or worsened (Evans, Ziebland, & McPherson, 2007). Common symptoms of vaginal cancer include abnormal vaginal bleeding, urinary frequency, vaginal pain during sexual intercourse and rectal discomfort in advanced stages of the disease (NICE, 2005; CDCP, 2014).

Early stage ovarian cancer is often asymptomatic, however, when symptoms present they are frequently vague or non-specific (Cooper, Polonec, Stewart, & Gelb, 2013). Common symptoms include: abdominal pain or pressure, bloating, changes in bowel or bladder habits, unexplained increase in abdominal size, appetite loss, fatigue, lower back pain or pain during sex (CDCP, 2014; Goff et al., 2004).

Ninety per cent of endometrial cancer cases present with a distinct symptom of vaginal bleeding (i.e. PMB, bleeding between periods, heavier periods than normal, abnormal vaginal discharge; NICE, 2005; CDCP, 2014). PMB is defined as an episode of bleeding twelve months or more after the last menstrual period (Scottish Intercollegiate Guidelines Network, 2002). PMB can be caused by endometrial hyperplasia, associated cell tumours of the ovary (Koukourakis et al., 2008), and can also be a symptom of cervical and vagina cancers (Rosenfeld, 2009). One in ten women presenting with PMB are diagnosed with endometrial cancer (Newell & Overton, 2012), however, due to the specific nature of the symptom and greater awareness of the abnormality of bleeding after menopause, many of the cases are diagnosed early (Brand, Dubuc-Lissoir, Ehlen, & Plante, 2000). Obese women have been identified as at high-risk of PMB and endometrial cancer (Breijer, et al, 2010; Feldman, Cook, Harlow, & Berkowitz, 1995).

Due to the somewhat vague nature of some signs and symptoms of gynaecological cancers, the literature suggests that an individual's subjective experience of their symptoms is often what drives a women to seek medical help and influences delay in diagnosis (Cooper et al., 2013; Evans, Ziebland, & McPherson, 2007). Psychological factors that lead to help-seeking are explained in Chapter 2.

Diagnosis

The process for diagnosing gynaecological cancers varies across sites. Women with symptoms often present initially to primary care physicians in general practice surgeries, and symptoms commonly include an irregular menstrual cycle, PMB, post-coital bleeding, palpable abdominal or pelvic mass, or vaginal discharge (NICE, 2005).

The UK healthcare service operates on a gatekeeping system, which means that primary care is the first point of contact when seeking-help for symptoms of cancer, and in most cases this is the only route to specialist care (Vedsted & Olsen, 2011). Within this system, the UK follows strict guidelines for the diagnosis of gynaecological cancers and will therefore be described in this section, in accordance with the current national guidelines (NICE, 2005; Pan Birmingham Cancer Network, 2015).

When presenting with symptoms of gynaecological cancers in the UK a doctor will conduct pelvic or vaginal examinations to determine the diagnostic pathway. If clinical features raise suspicion for cancer an urgent referral is made to the gynaecological cancers referral team (Pan Birmingham Cancer Network, 2015). For cervical cancer, a cervical smear test (i.e. papanicolaou cervical smear test [PAP]) is performed intravaginally to test for pre-cancerous and malignant cells present on the opening of the cervix and a biopsy is used to determine suspicion of cancer (NICE, 2005). Nevertheless, if presenting symptoms raise suspicion of cervical cancer, a General Practitioner (GP) may be referred directly to a gynaecologist who will undertake an examination and a biopsy of the suspicious areas. In some cases the PAP smear test result may indicate abnormality as pre-cancer. A gynaecological specialist will then conduct a colposcopy test where a microscope is placed inside the vagina to visualise the cervix and an excision will be conducted to cut away the affected cervical area (NHS Cancer Screening Programmes, 2010). A cone-shaped biopsy is sometimes used to remove a larger area of cells (Cox, 1999; NHS Cancer Screening Programmes, 2010).

If a woman presents to her GP with suspicious symptoms of the vulva or vagina the doctor will conduct a pelvic examination and will make an urgent referral to a gynaecological specialist if cancer is suspected (e.g. symptoms of unexplained lumps or bleeding of the vulva due to ulceration; NICE, 2005; Royal College of Obstetricians and Gynaecologists, 2006). If a patient presents with symptoms of itching or pain in the vagina or vulva the doctor may choose to treat the patient for infection or dryness and make a referral if symptoms persist after treatment (NICE, 2005). When referred, a gynaecological specialist will conduct a full pelvic examination (i.e. checking the groin lymph nodes and rectum), and often a colposcopy and biopsy will be performed to visualise and test the lesion (Royal College of Obstetricians and Gynaecologists, 2006). Tests will determine the stage of the cancer, and recommended treatment. Most cancer diagnoses of the vulva and vagina are squamous cell carcinomas (i.e. affecting cells in the epidermal layer of the skin), accounting for 90% of all cancers of the vulva and 80% of vaginal cancer cases (Daling & Sherman, 1996; Woolas & Shepard, 1999).

If a woman presents at a GP surgery practice with symptoms indicative of ovarian cancer she will be referred for an ultrasound test at secondary care, and where cancer is suspected an urgent referral (to be seen within two weeks) will be made to a gynaecological specialist who will conduct a full vaginal examination and may test blood for increased levels of CA125 protein (i.e. a potential indicator of ovarian cancer; Menon et al., 2009; NICE, 2011). If cancer is detected further tests will be ordered to determine the stage of cancer. Tests may include: (a) vaginal or abdominal ultrasounds, (b) x-ray, (c) CT scan, (d) MRI scan, (e) laporoscopy (i.e. visual scope of ovaries via surgical abdominal insertion and biopsy), (f) abdominal fluid or chest fluid aspiration (i.e. to remove fluid build-up and check for cancer cells), or a laparotomy (i.e. a wider incision through the abdomen allowing for visual examination and biopsy of the affected area or full removal of cancerous cells if possible; NICE, 2005).

For suspicion of endometrial cancer, a GP may conduct blood and urine tests and perform an internal vaginal examination. If a woman who is not on HRT or is on Tamoxifen hormonal treatment for breast cancer and presents with PMB in a UK GP practice an urgent (2-week) referral will be placed for the woman to see a gynaecological specialist (Butler et al., 2010; NICE, 2005; Pan Birmingham Cancer Network, 2015). A gynaecological specialist may conduct vaginal or abdominal ultrasounds, imaging scopes (i.e. hysteroscopy) and may take a biopsy (i.e. small sample of cells removed from the affected area; NICE, 2005). If cancer is detected further tests will be ordered to determine the size and location (i.e. staging) of the cancer. Tests may include: (a) blood tests, (b) a chest x-ray (to identify spreading), (c) computerised tomography (CT) scan, (d) magnetic resonance imaging (MRI) scan, and/or (e) positron emission tomography (PET) scan (NICE, 2005). The policy for PMB Clinics in the UK provides national standardised guidelines for the referral of suspected cancer malignancy when presenting with PMB. PMB clinics provide a fast and effective pathway to investigation with the aim of excluding cancer as the cause (Butler et al., 2010; NICE, 2005; Pan Birmingham Cancer Network, 2015). The pathway ensures that patients are seen by gynaecological specialists within 2 weeks of referral and that if a patient requires assessment and treatment they are able to do so within 31 days of referral. Patients diagnosed with a gynaecological cancer must begin treatment within 62 days of referral to improve survival and treatment outcomes.

The stage of a cancer determines the relative size and location or spread of the cancer. Cancer cells are also graded to estimate the rate at which the cancer will grow or develop. Three grades exist to rate cancer cells ranging from low-grade or slow-growing cells (i.e. similar appearance to normal or well differentiated) to high-grade or fast growing cells (i.e. highly abnormal or poorly differentiated; Odicino, Percorelli, Zigliani, & Creasman, 2008; Prat, 2014; Sobin, Gospodarowicz, & Wittenkind, 2009). Prognosis and survival are improved greatly when cancer is detected early. See Table 1.2, depicting the stages of cancer development for each gynaecological cancer type.

Table 1.2.

Staging of Gynaecological Cancers Using a Combined Staging System of FIGO & AJCC (TNM)

Cancer Type	Stage	Description
Endometrial	1.A-B	Cancer contained in uterus lining begins to grow in muscular wall.
	2	Cancer spread to cervix.
	3.A-C.ii	Cancer affecting outer uterus and/or ovaries and fallopian tubes grows to vagina and to abdominal lymph nodes (stage 3C.ii).
	4.A-B	Cancer spread beyond uterus to surrounding organs (bowel/bladder to distant body organs.
Ovarian	1.A-B	Cancer contained in one ovary and spreads to both ovaries.
	1.C	Stage 1A or 1B *and* cancer cells found on surface of one ovary, or in fluid taken from abdomen, or an ovary ruptured.
	2.A-B	Cancer spread outside ovaries to pelvis. Uterus/fallopian tubes or other pelvic organs.
	2.C	Stage 2A or 2B *and* cancer cells found in abdominal fluid.
	3.A-C	Small tumours in abdomen, <2cm tumours grow to tumours larger than 2cm with spread to nearby lymph nodes & bowel.
	4	Cancer affected more distant organs.
Cervical	1.A.i-ii.	Cancer contained within cervix and visible via microscope: from <3mm and <7mm wide to 3-5mm deep and 7mm or less wide.
	1.B.i-ii	Cancer larger, but still confined in cervix: <4cm to >4cm.
	2.A-B	Cancer affected upper part of vagina: <4cm to >4cm grows to cancer affecting tissues next to cervix.
	3.A-B	Cancer spread to lower vagina to pelvic tissues.
	4.A-B	Cancer spread to bladder/bowel and to distant organs.
Vulva	1.A-B	Cancer <2cm and grows to 1mm or less into the skin of vulva or perineum then grows to cancer >2cm *or* grows >1mm into skin.
	2	Cancer at any size that has spread to nearby structures (e.g. urethra, vagina, anus).
	3	Cancer spread to the lymph nodes in the right/left side of the groin.
	3.A-B	One/two lymph node metastases, <5mm *or* one lymph node, >5mm to three or more lymph nodes, >5mm *or* two or more >5mm.
	3.C	Any lymph node metastases.
	4.A-B	Cancer spread to nearby structures or lymph nodes and spreads beyond pelvic lymph nodes to distant organs.
Vaginal	0-1	Pre-cancerous lesion (commonly due to HPV infection) grows to small sized cancer contained within the vagina.
	2-3	Between stages 1 and 4.
	4	Cancer spread to the lymph nodes in the pelvis or organs. further away.

Adapted from Odicino et al. (2008), Sobin, Gospodarowicz and Wittekind (2009).

Treatment and Outcomes

Each site-specific cancer uses different treatment methodologies including surgery, radiotherapy and chemotherapy, and often a combination of these to remove, minimise or weaken the cancer and to relieve negative side effects as a means of improving quality of life in more advanced stages. See Table 1.3 showing the gynaecological cancer treatments used for each gynaecological cancer type.

Table 1.3.

Gynaecological Cancer Treatments

Treatments		**Cervical**	**Vulva**	**Vaginal**	**Ovarian**	**Endo-metrial**
Surgery	Lymph node removal	✓	✓	✓	✓	✓
	Removal of the cervix	✓				
	Partial/full vulva removal	✓	✓			
	Vaginal canal removal			✓		
	Cervix &/or womb removal (hysterectomy)			✓	✓	✓
	Removal of ovaries & fallopian tubes (salpingo-oophorectomy)				✓	✓
	Non-reproductive pelvic organs removal (debulking surgery)	✓	✓		✓	
Tissue removal	Remove small tumour & surrounding tissue		✓	✓		
	Biopsy	✓	✓	✓	✓	✓
Abdominal fluid removal & testing					✓	✓
Radiotherapy	Internal	✓	✓	✓	✓	✓
	External	✓	✓	✓	✓	✓
Chemotherapy		✓	✓	✓	✓	✓
Progesterone hormone treatment						✓

Early stages of cervical cancer (i.e. spread from the cervix to the upper part of the vagina) may be treated with a cone biopsy, surgical removal of the cervix (i.e. radical trachelectomy) or removal of the pelvic lymph nodes (i.e. lymphadenectomy) to detect further spread (Shaw, Luesley, & Monga, 2011). Internal or external radiotherapy may also be used post-surgery to reduce the risk of recurrence. It may be used in combination with chemotherapy (i.e. chemo-radiation) for larger, more invasive, tumours (Shaw, Luesley, & Monga, 2011).

Surgery is the most common form of treatment for cancer of the vulva and involves removal of the affected skin, surrounding healthy skin, lymph nodes and tumours on either side of the groin (Shaw, Luesley, & Monga, 2011). Lymph node biopsy is used to test lymph nodes on either side of the groin before removal. For early stages, removal of a one centimetre area of affected tissue will be conducted (Shaw, Luesley, & Monga, 2011). When cancer has spread to more advanced stages a radical partial or complete vulvectomy may be conducted to remove part (i.e. upper, one or both sides) or all of the lymph nodes of the groin (Shaw, Luesley, & Monga, 2011). If a vulvectomy is performed the surgeon will also conduct a surgical reconstruction to place a protective skin over the area. For very advanced stages of cancer, pelvic organ removal surgery will be conducted, like that of cervical cancer. Internal or external radiotherapy may be given pre or post-surgery to reduce the cancer size before operation, or to ensure all cancer is removed after surgery (Shaw, Luesley, & Monga, 2011). Chemo-radiation may also be used in advanced stages to suspend cancer spread and manage symptoms in palliative care.

In early stage cancer of the vagina, surgery may be used to remove the tumour along with the surrounding tissue. For more advanced stages, a vaginectomy may be performed (i.e removal of the vagina) followed by a vaginal reconstruction to create a new vagina (Cancer

Research UK, 2013e). Additionally, a radical or total hysterectomy may be performed, removing the womb, cervix and pelvic lymph nodes (Shaw, Luesley, & Monga, 2011). Internal or external radiotherapy and chemotherapy is often used in combination for moderate stages, for younger women who still wish to have children or before surgery to reduce the size of the cancer (Shaw, Luesley, & Monga, 2011).

Women diagnosed with Stage I ovarian cancers usually undergo a surgical total abdominal hysterectomy and salpingo-oophorectomy (i.e. removal of the ovaries, fallopian tubes, uterus and cervix). In most cases the surgeon will also remove the fatty tissues close to the ovaries (i.e. omentum) and abdominal fluid (i.e. abdominal or peritoneal washing) and may perform lymph node biopsies to assess for cell grade (Shaw, Luesley, & Monga, 2011; Souhami & Tobias, 2003). For younger women who wish to have children, the unaffected ovary and uterus will not be removed. Women diagnosed with stage two and three ovarian cancer will undergo a total abdominal hysterectomy and salpingo-oophorectomy along with a more serious surgery described as *de-bulking* surgery to remove as much of the tumour as possible, the omentum, lymph nodes of the abdomen and pelvis, the appendix, abdominal lining and potentially a piece of the bowel (Shaw, Luesley, & Monga, 2011). Chemotherapy may be used pre and post-surgery to decrease the tumour size for surgery and to aid in recovery. Women diagnosed with stage four ovarian cancer may be given chemotherapy to decrease the tumour size or radiotherapy to reduce pain and bleeding and improve quality of life in palliative care (Shaw, Luesley, & Monga, 2011).

Most endometrial cancers are caught in an early stage (Plataniotis & Castiglione, 2010). This is likely due to the distinct nature of PMB symptoms, and have not yet spread beyond the uterus, as such most cases are treated by surgical removal of the uterus (i.e. hysterectomy; Shaw, Luesley, & Monga, 2011; Rose, 1996). Usually a total removal of the uterus, fallopian tubes and both ovaries (i.e. hysterectomy with bilateral salpingo-oopherectomy) is recommended along with abdominal fluid testing and removal of lymph nodes close to the uterus. Surgery is occasionally followed by radiation therapy to reduce the risk of recurrence (Shaw, Luesley, & Monga, 2011; Souhami & Tobias, 2003). Radiotherapy is delivered internally (i.e. through the vagina) or externally (i.e. over the body) and primarily to individuals who are unable to have surgery due to health issues (e.g. for morbidly obese patients with anaesthetic risks during surgery), or in cases of cancer recurrence after a hysterectomy (Shaw, Luesley, & Monga, 2011). Hormonal treatment with progesterone or chemotherapy treatment may also help to shrink the cancer and improve symptoms for individuals in advanced stages of palliative care (Shaw, Luesley, & Monga, 2011).

Importance of Early Diagnosis

For most cancers the survival rate is associated with the stage at time of diagnosis, highlighting the importance of early detection and screening.

According to recent data from the International Cancer Benchmarking Partnership, the UK has lower survival rates one year after diagnosis for some cancers (including ovarian cancer) when compared to other countries with similar cancer control strategies (Coleman et al, 2011). It is hypothesised that this may be due to the later stage of cancer at time of diagnosis, which would result in poorer survival rates after one year. However, due to the lack of accurate recording of staging in gynaecological cancers in the UK, data to confirm this hypothesis are not readily available (Department of Health, 2012; Low, Simon, Wardle, & Memon, 2013b). For example, vaginal and vulval cancers UK figures on stage distribution are not available, which may be because these cancers are significantly more rare when compared to the incidence of the other three (Cancer Research UK, 2014a; Low et al., 2013b). Additionally the stage-distribution figures for diagnosis of endometrial cancer in the UK are not readily available, although it has been reported that most cases are diagnosed in the early stages (Plataniotis & Castiglione, 2010). However, given survival rates differ greatly between early and late stage gynaecological cancers, showing 98% survival for Stage 1 endometrial cancers and 35% for Stage 4 (Cancer Research UK, 2014c), and 98% survival for Stage 1 ovarian cancers and 41% for Stage 4 (Cancer Research UK, 2014d) evidence suggests that early diagnoses may be beneficial. A study by Torring, Frydenberg, Hansen, Olesen, Hamilton, and Vedsted (2011) found that increased time to diagnosis from presentation at primary care predicted higher mortality in patients presenting with symptoms of colorectal cancer, highlighting that lower survival rates for later stage diagnosis may be due to diagnostic (system) delays and poorer management of women diagnosed at more advanced stages (Low et al., 2013b). Nevertheless encouraging women to seek help promptly may improve outcomes.

For cervical cancer, 75% of women in the UK are diagnosed at Stage I. This relatively high percentage of early stage diagnoses is likely a result of the national standardised screening programme for cervical cancer (NHS Cancer Screening Programmes, 2012). Amongst the five sites for gynaecological cancers, cervical cancer is the only one to have a national standardised screening programme, whereby PAP smear tests and vaccinations are used to test for, and prevent HPV infection that may occasionally also present in other HPV-related cancers (i.e. cancers of the vulva and vagina). Vaccinations are available to young women aged 11 to 26 years in all developed countries (Dowling, Klabunde, Patnick, & Ballard-Barbash, 2010; Whitlock, Vesco, Eder, Lin, Senger, & Burda, 2011). HPV vaccines (e.g. Gardasil and Cervarix) help to protect women against the most common strains of HPV (Bosch & Harper, 2006; Koutsky et al., 2002). Vaccinations are recommended for adolescent and pre-adolescent young women before they become sexually active (Department of Health England, 2013). The UK cervical screening programme invites women from 25 to 64 years of age to attend routine cervical smear tests (Department of Health England UK, 2013). Currently there is no national screening programme for ovarian cancer in the UK, however, results of randomised controlled trials suggest that a simple blood test (i.e. testing for a protein CA125) and vaginal ultrasound are promising new approaches in the detection of early-stage ovarian cancer and data from an ovarian cancer screening trial called The United Kingdom Collaborative Trial of Ovarian Cancer Screening may influence policy to implement a blood test screening programme for ovarian cancer and transvaginal ultrasounds screening for endometrial cancer amongst post-menopausal women in the NHS (Buys et al., 2011; Jacobs et al., 2011; Skates, 2013). Ovarian cancer may also be detected by pelvic examination at regular PAP smear visits, however this is more effective in detecting later stages of ovarian cancer (Westhoff, Jones, Guiahi, 2011).

Given the differences between early and late stage survival rates at time of diagnosis for gynaecological cancers and the current lack of screening programmes for other gynaecological cancers (i.e. endometrial and ovarian), reducing the number of later stage diagnoses in unscreened women is suggested to improve outcomes (Low et al., 2013b). Therefore, encouraging women with symptoms to promptly seek help by consulting their GP is important, particularly given the number of women who do not seek help at an early stage and are instead diagnosed with a gynaecological cancer through emergency presentation or by death certificate only (30% of ovarian, 8% of uterine and 12% of cervical cancer diagnoses; National Cancer Intelligence Network, 2010). Encouraging women to seek help through primary care may prevent such late stage diagnoses.

Despite acknowledging that encouraging prompt help-seeking for symptoms may increase GP consultation rates (Stapley and Hamilton, 2011), it is likely that the rate of women not seeking help from the GP is greater (Low et al., 2013b). While acknowledging that these symptoms are not likely to be cancerous, it is still suggested that women should be encouraged to seek help as a means of increasing earlier cancer diagnoses and allowing for the detection of other potentially treatable conditions, such as endometriosis, fibroids, polyps, infections and skin irritation or dryness due to a lack of hormones after the menopause (Low et al., 2013b).

Early Detection Amongst Obese Women

Obese individuals have been suggested to be less likely to participate in screening programmes than non-obese women (Aldrich & Hackley, 2010; Amy, Aalborg, Lyons, & Keranen, 2005; Aphramor, 2012), resulting in more advanced presentations of gynaecological cancers for these women (Ardnt, Sturmer, Stegmaier, Ziegler, Dhom, & Brenner, 2002; Maruthur et al., 2009). Obese women are reported to have greater body dissatisfaction, which may impact on the decision to seek medical help, and may act as a barrier to help-seeking and participation in gynaecological and breast screening programmes (Alegria Drury & Louis, 2002; Ridolfi & Crowther, 2013) even when controlling for factors such as age, race, socioeconomic status, and comorbidities (Aldrich & Hackney, 2010). Reasons for non-attendance in health screening programmes for obese women also included embarrassment, accessibility barriers (i.e. mobility, socioeconomic barriers) perceived weight-stigma as experienced through poor doctor-patient communication (Aldrich & Hackney, 2010; Phelan et al., 2015; Puhl & Heuer, 2008) and concerns about limitations with equipment (i.e. weight/size restrictions for equipment; Aldrich & Hackney, 2010; Uppot, 2007). Similar factors have been suggested to facilitate the delayed presentation of obese women at healthcare services, with lack of symptom and disease knowledge and negative previous experiences of weight-stigma in healthcare being the key barriers to healthcare utilisation for obese women (Befort et al., 2006; Phelan, Burgess, Yeazel, Hellerstedt, Griffin, & van Ryn, 2015; Soliman et al., 2008). Still, it should be acknowledge that research to date has not specifically looked at obese women seeking help for potential symptoms of gynaecological cancers. If reduced survival rates for obese women presenting with gynaecological cancer symptoms is explained by a reduction in attendance at screenings (Maruther et al., 2009), obese women should be encouraged to seek help promptly for symptoms of gynaecological cancers, particularly given that the national screening programmes in the UK are limited to cervical screenings only.

Role of the Healthcare Professional in Early Detection

Healthcare professionals also play a role in the early detection and diagnosis of gynaecological cancer symptoms by recognising the vague or non-specific symptoms indicative of some gynaecological cancers and responding by providing appropriate referrals down the diagnostic pathway. Furthermore healthcare professionals play a key role in influencing help-seeking behavioural amongst patients and encouraging prompt help-seeking for symptoms.

Literature suggests that delay in early detection and help-seeking may be due to a reduced awareness about the symptoms and risks of gynaecological cancers (Boxell et al., 2012; Sheikh & Ogden, 1998; Jayde, White & Blomfield, 2010; Soliman et al., 2008). This lack of awareness is further perpetuated by the vague and non-specific symptoms of gynaecological cancers, which may lead to misinterpretation of symptoms as benign by patients *and* healthcare professionals who may relate symptoms to benign (Evans, Ziebland, & McPherson, 2007) or weight-related issues (e.g. bloating, changes in bowel habits, back pain), thereby acting as a barrier to individuals requiring help for malignant symptoms of gynaecological cancers (Macleod et al., 2009; Smith, Pope, & Botha, 2005). Furthermore, a study on medical help-seeking delay, by Amy and colleagues (2005) attributed delayed help-seeking gynaecological cancer symptoms amongst obese women to disrespectful interactions and perceived attitudes of healthcare professionals which stigmatised overweight and obese women. Furthermore, a study exploring the barriers and facilitators of help-seeking for breast and cervical cancers reported that women believed that a positive and trusting relationship with their GPs facilitated help-seeking amongst all women regardless of size (Marlow, McGregor, Nazroo, & Wardle, 2014). Therefore findings highlight the importance of healthcare professionals beliefs and perspectives as well as gynaecological cancer knowledge in encouraging women to seek help promptly for symptoms and in facilitating early detection and timely diagnoses of gynaecological cancers amongst obese and non-obese women alike.

To date, research has not investigated to beliefs and perceptions of healthcare professionals working with obese patients, which could inform investigation into early detection and diagnoses of gynaecological cancers amongst this group. Healthcare professionals' research can illuminate important perspectives on issues that affect quality of care and disease outcomes (Clark, 2005) and provide insight into the identification of patient barriers to care and the experience of health services (Al-Busaidi, 2008). Such research can inform patient research to develop a cohesive understanding of the patient and healthcare professionals perspectives on barriers and motivators of help-seeking for symptoms of gynaecological cancers, given that both the patient and the healthcare professional play key roles in early detection and the utilisation of healthcare services.

Early detection of most cancers is dependent upon individuals recognising a symptom as meeting sufficient severity to seek medical help (Rob et al., 2009), this includes symptoms of gynaecological cancers (Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009). However, given that many of the symptoms of gynaecological cancers are non-specific and associated with a variety of benign conditions (e.g. bloating, gas pains, indigestion, urinary urgency, lower back pain) the nature of the symptoms may contribute to delayed help-seeking and diagnosis of gynaecological cancers (Evans, Ziebland, & McPherson, 2002), which may contribute to later stage disease at time of diagnosis, particularly for ovarian cancer (Ryerson, Eheman, Burton, McCall, Blackman, Subramanian, 2007). However, we also know that the healthcare professional plays a role in the early detection and diagnosis of symptoms and recognising such non-specific symptoms as potential symptoms of cancer.

The rate of growth and early signs of cancer may vary by cancer type, therefore the evidence for this association in gynaecological cancers is not as clear as the evidence for other common cancers. For example a study by Ardnt and colleagues (2002) identified that patients with poorly differentiated tumours of the breast were more likely to delay seeking help, leading to later-stage diagnosis and poorer outcomes. This study and others (e.g. Caplan, 2014) suggest that difficulty recognising a symptom influences time to help-seeking and stage of diagnosis for breast cancer. The CDCP (2014) in the United States recommends that individuals should seek help for gynaecological symptoms within two weeks of initial presentation, however an exception is made for abnormal vaginal bleeding, for which immediate care is recommended (Cooper et al., 2013). Nevertheless, limited research has been done to investigate time to help-seeking for potential symptoms of cancer with more research investigating awareness of gynaecological cancer symptoms and anticipated or hypothetical time to help-seeking (Cooper et al., 2013 Low et al., 2013a; see Jones & Johnson, 2012), or asked non-temporal questions about weather or not women sought help for symptoms and their primary pathway to diagnosis (Low et al., 2013b).

Summary

Gynaecological cancers vary by incidence, risk factors, signs and symptoms, treatments and outcomes. Nevertheless, it is clear that these forms of cancer are associated with a strong worldwide disease burden. Early detection and prompt help-seeking can improve treatment and survival outcomes and allow for treatment of non-cancerous gynaecological conditions. However, gynaecological cancer symptoms present particular challenges with the recognition of vague and non-specific symptoms, which are often not recognised as warning signs of cancer or are not severe enough to seek medical help.

These issues are particularly important amongst obese women, who are at higher risk of developing gynaecological cancer and are more likely to delay attendance at regular screenings, further increasing their risk of later stage diagnosis for gynaecological cancers, particularly ovarian, cervical and vulval cancers, which can be diagnosed as a result of regular screenings. Therefore, understanding what leads women to seek help and what influences the process of delay is essential to inform help-seeking research and intervention development in this population given that this information is not yet known. Despite the high incidence of gynaecological cancers some individuals still delay seeking help and it is important to identify populations at greatest risk of delay. The following chapter provides an overview of the health behaviour theories that built and understanding for medical help-seeking behaviour and provides insight into the psychological investigation of help-seeking for symptoms of cancer.

CHAPTER 2: LITERATURE REVIEW- PSYCHOLOGICAL HELP-SEEKING THEORY

The process of help-seeking is a dynamic one wherein an individual recognises, interprets and responds to a bodily change or symptom by making an active decision to towards move toward health by communicating an appraised health issue to another (Cornally & McCarthy, 2011). This chapter reviews help-seeking theories and models in the contexts of physical health and illness, where help-seeking is defined as a response to observed health changes and a process toward health-seeking behaviour (O'Mahony & Hegarty, 2009). The chapter introduces help-seeking by first outlining what a symptom is, then presenting an overview of the key theories and models that inform our understanding of help-seeking behaviour, followed by a description of the factors that are known to influence processes of symptom perception to appraisal. Finally, specific constructs that affect decision-making processes and associated behavioural responses are described.

Symptoms and Behavioural Response

What is a symptom? The decision to seek help begins with a complex process of symptom perception (i.e. noticing a symptom) and interpretation (i.e. understanding of a symptom). This process can be viewed as the recognition of biologically based and *objective* bodily sensation(s) identified as signs, wherein a sign is a signal of abnormality that is detectable by the individual as well as others (Scott, 2010). Signs often act to evaluate or determine severity of disease and formulate strategies for clinical management (Dodd et al., 2001). Alternatively, symptoms are defined as the *subjective* experience of a physiological event (Scott, 2010), which can include changes in the biopsychosocial functioning, sensations or cognitions of an individual (Dodd et al., 2001). A symptom is conceptualised as a multidimensional experience of a bodily condition that is experienced by the affected person as a departure from normal functioning (i.e. bodily change), and which is not understood by others until this experience is communicated (MacBryde & Blacklow, 1983; Rhodes & Watson, 1987). *Physical symptoms* are described through the biomedical and cellular functioning mechanisms. Nevertheless, some experiences are described by psychologists and psychiatrists as *somatic symptoms*, which acknowledges the influence of psychological and social processes on the perception and potential development of symptoms (Kroenke, 2003). For example, somatic symptoms of chronic obstructive pulmonary disease can include: fatigue, anorexia and weight loss (Dorwick, 2005). The two terms *physical* and *somatic* are used synonymously in the research literature without defining the cause of symptoms. It is important for the purpose of the present thesis, that both the biological and psychosocial perspectives of symptoms be acknowledged given that many symptoms cannot be explained by the biomedical model (e.g. medically unexplained symptoms, somatic symptom disorder, functional somatic syndromes; American Psychiatric Association, 2013; Barsky & Borus, 1999; Reid, Wessely, Crayford, & Hotopf, 2010). In the current chapter physical symptoms are understood as perceived changes in bodily functioning. This view includes both *normal* and *pathological* physiological functioning and acknowledges the influence of cognition, emotion and environmental factors on the perception and experience of symptoms.

Behavioural response to symptoms. When the UK's National Health Service was established in 1948, the process of help-seeking was built on the assumption that if individuals perceived themselves to be unwell and in need of medical attention they would intuitively seek out the help of medical services (Hardey, 1998). It is now common knowledge that individuals who feel unwell often do not seek help, and those who seek help are at times not unwell (Last, 1963; Moffat, 2010). This phenomenon is referred to as the *illness iceberg* (Last, 1963). Hannay (1979) described this phenomenon in a UK survey study which showed that a significant number of serious conditions were found to be reported (e.g. anaemia, diabetes, cancer, bronchitis), whilst many were never brought to the attention of GPs and many patients who attended GP services did not receive appropriate referrals for serious conditions, whereas others with more "trivial" symptoms did. A review by Verbrugge and Ascione (1987) found that individuals experiencing physical symptoms often chose to self-manage through non-prescription medication and reduced physical activity. Results of the study highlighted a key difference in the behavioural responses to acute and chronic health problems, such that acute illness responses were motivated by the desire for immediate, short term symptom relief, and chronic illness responses involved strategies of care over time. Self-management strategies were determined by an individual's personal characteristics (i.e. social roles and attitudes) and available resources.

The above research highlights the important role GPs play in help-seeking, as they are often the first point of contact for individuals seeking help for physical symptoms. Nevertheless, there remain many individuals who do not seek medical help (e.g. individuals who self-manage symptoms) while others seek help for trivial symptoms or seek help but do not receive critical referrals for serious conditions.

Understanding help-seeking behaviour: Overview of the key theories and of models

Previous research allows for development of inquiry into the complex psychosocial influences on symptom perception and the decision to seek medical help. Furthermore, it is important to acknowledge from the beginning that deciding to seek help is only one of many possible responses to symptom perception, thus it does not predict medical help seeking alone (Scott, 2010).

The Andersen Delay Model (Andersen, Cacioppo, & Roberts, 1995; Safer, Tharps, Jackson, & Leventhal, 1979) proposes a general framework that presents sequential stages from the detection of a physical symptom to treatment, assuming treatment is necessary (See Figure 2.1.). Andersen's delay model is a five-stage model that describes decisional processes which each have the potential to delay presentation to healthcare services, subsequently delaying diagnosis and treatment (Andersen, Cacioppo, & Roberts, 1995; Scott, Walter, Webster, Sutton, & Emery, 2013). Delay can be measured in days or years after an initial symptom is detected to the time an individual seeks help or receives a diagnosis (Safer et al., 1979) and is often based on the clinical implications of delay on a disease (i.e. the morbidity and mortality). Nevertheless, there is no consensus on a definition of delay within the literature and definitions are often disease specific (Scott & Walter, 2010; Sisler, 2003; Walter, et al., 2012).

In a study employing the Andersen model (Andersen et al., 1995) to understand gynaecological cancer delay amongst other cancers, and Hansen and colleagues (2008) further clarified the stages by identifying factors most responsible for the delay in each stage amongst men and women with various cancer types (including ovarian and endometrial cancers). Proposed stages of delay included patient delay (e.g. appraisal of symptoms as not serious enough to seek medical attention), healthcare professional (HCP; e.g. symptoms misdiagnosed as benign by GP or referral not made) and system delay (e.g. appointment and referral delays). Patient delay included the *perceptual delay* stage (which was added to Figure 2.1 to take into account factors that influence sensory perception) and is understood as the time between the presence of a physical symptom and actual detection of the symptom by the individual. *Appraisal delay* (i.e. misattribution) refers to the time between first detection of a symptom and inferring it as a result of illness, and *illness delay* refers to the time between inferring illness and realising that one needs medical care. The complete Andersen et al. (1995) model of help-seeking behaviour includes three additional stages of healthcare delay: a) *behavioural delay* (i.e. time from the decision to seek medical attention to the action or first contact with medical care), b) *scheduling delay* (i.e. time from contacting healthcare to attending the scheduled appointment) and c) *treatment delay* (i.e. time between first healthcare visit and treatment onset), which may also be preceded by a referral delay (added to Figure 2.1 to include alternate diagnostic pathways). Furthermore, scheduling delay may be described as a system delay if a patient is unable to book an appointment with his/her GP due to insufficient appointment availability or a patient delay if the patient fails to attend their scheduled appointments with a HCP. HCPs are described as providers of clinical services (i.e. with the ability to order investigations, diagnose, treat, or engage with treatment providers; Weller et al., 2012). Previous literature suggests removal of the term *delay* (e.g. Corner, Hopkinson, & Roffe, 2006; de Nooijer et al., 2001; Scott et al., 2013; Walter et al., 2012), as there is an implied responsibility that accompanies the term and often blames the patient without investigating the external factors that have impacted on a patient's delay. These external factors may be those outside of a patient's control (e.g. accessibility of services, healthcare scheduling delay). Furthermore, definitions of delay are often ambiguous or are reported without providing evidence for impact of delay on clinical outcomes (Walter et al., 2012), thus *time-interval* replaced this term in Figure 2.1 as suggested by Walter et al. (2012) in their review of the model. This lays the foundation for the focus and structure of this chapter, which describes an overall process of help-seeking rather than a focus on delay.

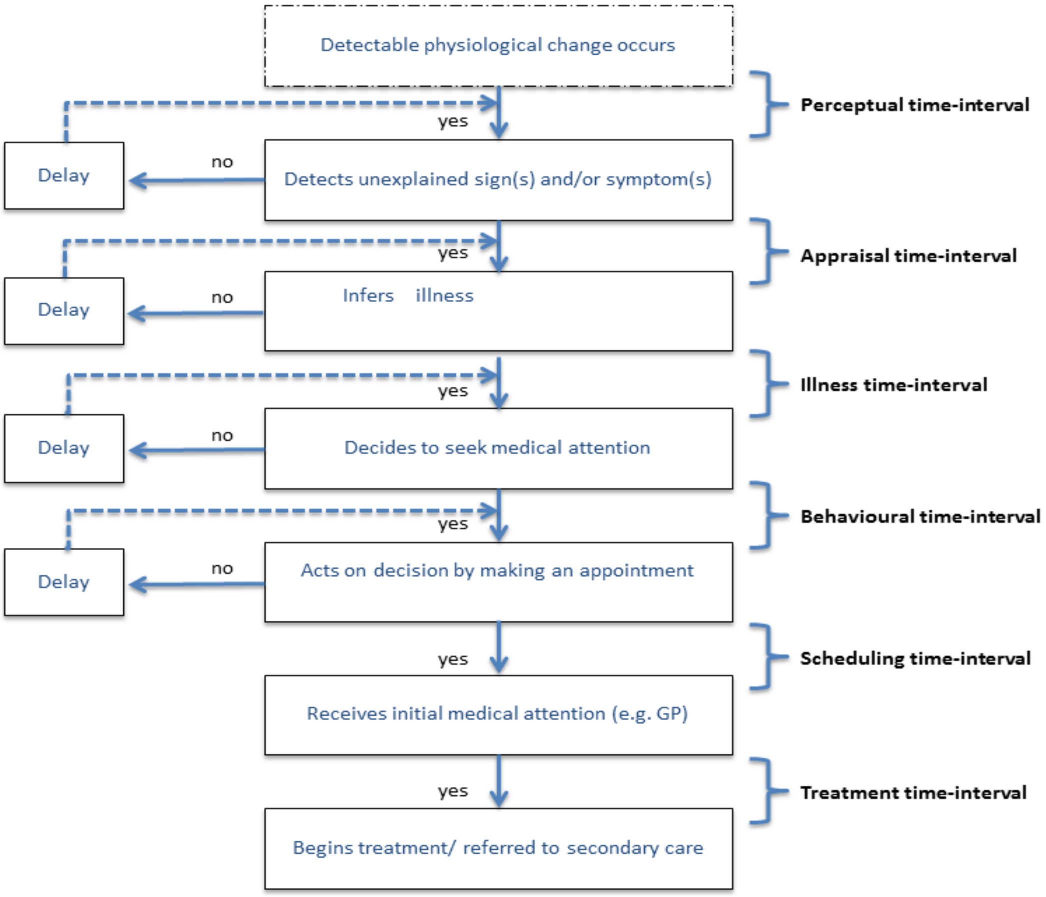

Figure 2.1. Adapted Andersen's stage model of help-seeking behaviour. Adapted from The General Model of Total Patient Delay proposed by Andersen, Cacioppo, and Roberts (1995).

In a systematic review, Walter et al. (2012) found support for the use of Andersen's stage model by acknowledging clearly identifiable stages and the acknowledgment of potential delays in understanding the process of help-seeking for symptoms of cancer. There is strong evidence to suggest that appraisal represents the stage of greatest delay, suggesting that it is attributable to 60% of the overall delay, and was most significantly impacted in women diagnosed with gynaecological cancer and those undergoing investigation for breast symptoms (Andersen et al., 1995; Scott, 2010) (discussed in the section below). Evans, Zeibland and McPherson (2007) report that delay is often due to a misattribution of symptoms to benign conditions, and similar findings were reported in the Smith et al. (2005) and Gould, Fitzgerald, Fergus, Clemons and Baig (2010) studies. Petrie and Weinman (2003) describe Andersen's stage model as useful in acting as a basic road map for the journey toward help-seeking, which provides the names of towns one will pass through, though it does not provide any information about these towns. Therefore, the model creates a basic framework for understanding the decisional stages one encounters when progressing toward medical help-seeking, however, it does not enable understanding for how these decisions enable movement from one stage to the next or how one comes to decide to seek help. Walter et al. (2012) criticised Andersen's separation of stages, suggesting that illness and appraisal delay should not be represented by independent stages, given that patients may experience a symptom as immediately concerning and seek help immediately (conceivably merging these two stages), while others may seek help for symptoms without acknowledging it as a sign of illness. This merging of stages creates a challenge when assessing the distinct stages of appraisal, illness and behavioural delay, and in describing how an individual comes to perceive that they are not well. Furthermore, the model depicts a linear movement through stages and does not allow changes in one's interpretation and appraisal of symptoms, nor does it include the psychosocial influences on these decisions (Scott et al., 2013; Scott, McGurk, & Grunfeld, 2007; Walter et al., 2012).

Criticisms of help-seeking models describe the false presumption that patients seek help for symptoms primarily for the purpose of treatment, when many patients will often seek medical advice for other reasons (e.g. reassurance, social contact, symptom relief; St. Claire, 2003). Before discussing these psychological and psychosocial factors that influence help-seeking it is important to gain a broader understanding of the theoretical underpinnings that guide this processes (of perception, appraisal, and making the decision to act and behave).

Symptom perception, appraisal and help-seeking behaviour theory

Information processing. The decision to seek help begins with the initial detection of bodily change(s), interpretation and the subsequent appraisal of these changes as potential symptoms of illness. To gain an understanding of this information processing system we revisit the biological and psychological models from Chapter 1, which are presented here in greater detail to build an understanding of the complex processes involved in symptom perception. The biological model approach to information processing describes a data-driven symptom perception in which somatic sensations are experienced and rated by quality (e.g. salience or severity) and quantity (e.g. persistence or variety). This process is described as a bottom-up objective process of symptom recognition (Scott, 2010; St. Claire, 2003) and assumes passivity of the experiencer. The biological approach provides an incomplete understanding of the process of symptom perception given that it does not take into account the environmental factors and cognitions that affect somatic awareness and symptom recognition (Andersen, Cacioppo, & Roberts, 1995). For example, the biological approach to explain pain would suggest that the level of pain is proportionate to the amount of tissue damage, and individuals with greater tissue damage would experience a greater degree of pain. However, the experience of pain is influenced not only by the biological processes within the body, but also by social, cultural and psychological factors (Keefe, Lefebvre, Egert, Affleck, Sullivan, & Caldwell, 2000). The Beecher (1956) study presented evidence of World War II soldiers who reported little or no pain despite the severe injuries they endured in battle. The psychological model, on the contrary, uses a conceptually driven approach that recognises the influence of cognitions (i.e. expectations, beliefs, understandings) and emotions in an active approach to the perception of bodily sensations. It describes a top-down process that emphasises the relationship between how one understands their symptoms and how one experiences bodily sensations. Using the example described above, an individual may experience severe pain and distress with a minor injury, while another with more severe injuries may experience minor pain with little or no distress, depending on influencing factors in their environment. Both models interact, allowing an individual to identify a symptom, label it, and interpret the bodily information as attributable to disease or an otherwise benign condition. Pennebaker (1982) proposes that perceiving physiological stimuli functions as an identical process to that of receiving environmental stimuli (e.g. auditory and visual information), therefore physiological sensing is subject to similar biases. Cacioppo and colleagues (1986) posited that this process of attribution exists in all human beings, as we are all motivated to develop an explanation for the presence of any bodily sensation.

Nevertheless, as we have seen in the previous chapter and the section above, the frequent ambiguity of symptoms create issues when attempting to recognise and interpret symptoms as severe enough to require medical help. Furthermore, the identification of the appraisal stage as the stage of greatest delay, suggests that there are additional cognitive-perceptual processes that are influenced by psychosocial factors (e.g. emotional state, sociocultural environment, one's understanding of illness and previous experience of illness; Pennebaker, 1982; Cioffi, 1991). Therefore the information-processing models are not adequate in understanding all key influences.

The following sections will therefore describe a series of models that outline the processes of help-seeking, from symptom perception to medical help-seeking behaviour, and will present an overview of three key models that build a foundation for the present PhD research.

Symptom perception model. The beginning of the help-seeking process begins with the detection of a physiological change or symptom (i.e. symptom perception), thus it is important to gain an understanding of this crucial first stage, before introducing help-seeking models that focus on the detection and appraisal of health-threats and the volitional actions taken toward help-seeking behaviour more specifically. Contrary to the assumptions of the biomedical model, non-physiological factors exist and influence whether symptoms will be perceived and how they will be interpreted. Here, the *Symptom Perception Model* (Gijsbers van Wijk & Kolk, 1997; Kolk, Hanewald, Schagen, & Gijsbers van Wilk, 2003) is presented to gain an understanding of the biological, psychological, and social factors that influence the perception of bodily changes and symptoms. While several integrative models of symptom perception have been described in the literature (e.g. Cioffi, 1991; Kirmayer & Taillefer, 1997; Pennebaker, 1982; Petersen, van den Berg, Janssens, & Van den Bergh, 2011), one key model is presented in this chapter. The Symptom Perception Model incorporates the *cognitive-perpetual model* (Cioffi, 1991) and the *competition of cues* hypothesis (Pennebaker, 1982), highlighting a number of psychological, social and environmental factors that influence symptom perception (Goodwin, Fairclough, & Poole, 2013). See Figure 2.2. Despite the recognition of attributional processes in the model, these processes are not described in as much detail as the previous perceptual processes, therefore the self-perception processes will form the primary focus of this section.

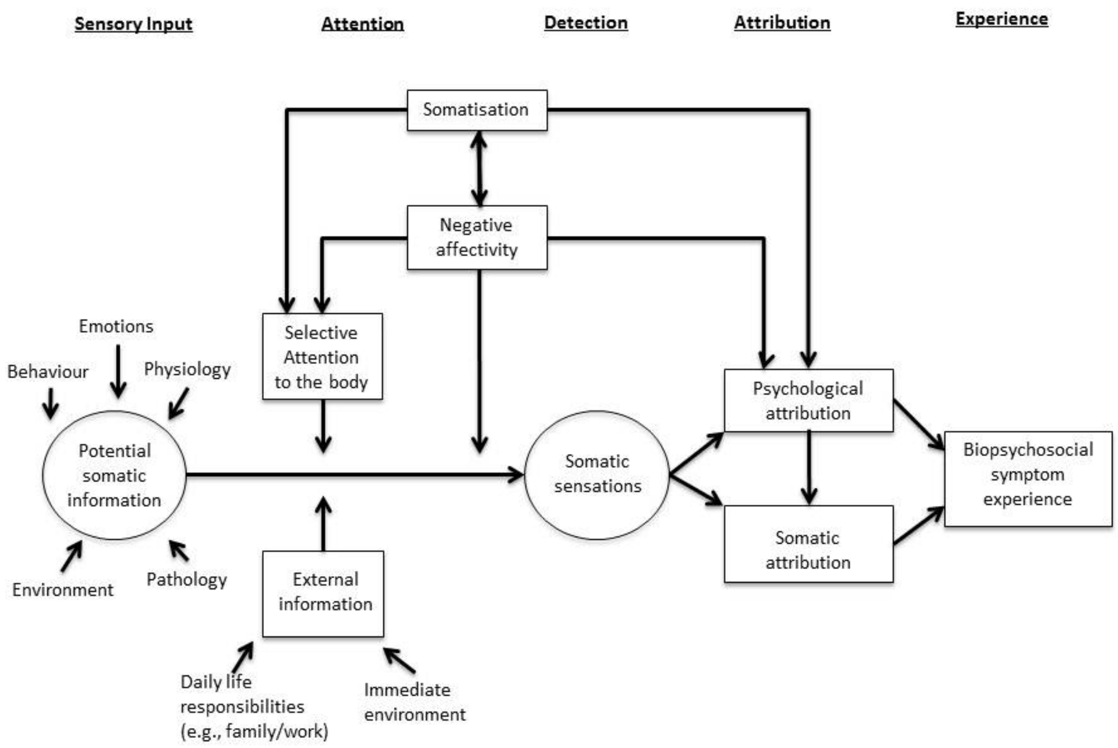

Figure 2.2. Symptom Perception Model. Adapted from Gijsbers van Wijk & Kolk (1997) and Kolk et al. (2003).

Based on Pennebaker's (1982) research, the model assumes: (a) humans have a limited capacity to process information at any one time, receiving more information than they are able to process at any given time; (b) attention to sensory information is selective; (c) sensory information alternates between information from the external (environmental) and internal (bodily) sensory information producing a competition of cues, to win the attention of the limited attentional resources available at any one time; (d) perception involves both bottom-up (data-driven) and top-down (conceptually driven) processes which work concurrently; (e) the small amount of information received by one's attention is partially determined by their cognitive and personality traits and partially due to the clarity and intensity of available information (Gijsbers van Wijk & Kolk, 1997).

The model identifies psychological, environmental, social and biological factors that affect the level of attention given to bodily signals, recognising that novel somatic information (e.g. pain) is likely to have greater attention-grabbing properties than other existing bodily signals. This is due to a concept called *attention-regulation* that decides to what degree sensory information is selected for processing, and is based on the assumption that only a small amount of information is actually processed into awareness, despite the myriad of sensory receptors activated in the body at any one time (generating information about bodily organs and internal functioning; Kolk et al., 2003).

The symptom-perception model introduces three key concepts that influence how somatic information is perceived, thus determining whether a somatic sensation will be attended to, and further appraised as a symptom. These concepts include: Self-directed attention toward the body (i.e. *selective attention* to normal physiological processes), disposition (e.g. *negative affect*) and *external environmental* factors (i.e. ratio of information from the body to information from the environment) that influence attention to and awareness of bodily sensations. Selective attention to the body is expected to lower the threshold for symptom detection (Kolk et al., 2003), thereby heightening the sensitivity for somatic information processing (Cioffi, 1991; Pennebaker, 1982). Moreover, selective attention is associated with heightened physiological or emotional arousal (Rief & Barsky, 2005). Negative affectivity is defined as “the tendency to experience and report negative mood states” (Kolk et al., 2003, p.2344) and examples include anger, depression, fear, anxiety and guilt (Watson & Clark, 1984). Negative affectivity increases selective attention to bodily sensations (Gendolla, Abele, Andrei, Spur, & Richter, 2005; Watson & Pennebaker, 1989) by lowering the detection threshold for physical sensations, making bodily changes more easily detectable by consciousness. Several studies have reported an association between negative affect and increased symptom reporting (e.g. Vassend & Skrondal, 1999; Williams & Wiebe, 2000). Furthermore, Kolk et al. (2003) suggests that individuals with high negative affect are more likely to have a higher selective attention to the body, therefore proposing that selective attention mediates the indirect effect of negative affect on reporting of symptoms.

Finally, given a limited aptitude for attention, there is on-going competition between internal cues of the body and external cues of the environment (*competition of cues hypothesis*; Pennebaker, 1982). Therefore, the more demands placed on one's attention by their external stimuli, for example in upholding daily life responsibilities of work and family, the less one is aware of their bodily *sensation,* unless the external stimuli becomes a stressor and emotionally distressing. Conversely, when the external environment lacks stimulation, attention is directed elsewhere, often internally to heighten attention to bodily sensations. Experimental studies investigating the perception and reporting of symptoms post-exercise indicated that individuals reported physiological sensations (e.g. heart rate and fatigue) more intensely when placed in the low environmental stimuli condition or when conditions were manipulated to draw attention to bodily functions of heart rate and breathing (through the use of headphones), as opposed to a highly stimulating environmental condition (Pennebaker & Lightner, 1980; Fillingim & Fine, 1986). This competition of cues hypothesis assumes that individuals play a passive role in receiving somatic information within their environment. Nevertheless, individuals are veritably engaged in active perceptual processes, which require the perceptions and appraisal of various somatic information. Symptoms are appraised by an individual once sensations are brought to attention and labelled as physical symptoms.

Appraisals are developed through cognitive representations of symptoms constructed from prior experiences with, or ideas about, illness and disease that form easily accessible templates for efficient information processing (i.e. *illness schemata*; Kolk et al., 2003).

Interpretations about a given symptom experience are then made in line with the schema, thus guiding our interpretation of symptoms, which may change based on the chosen schema. Schemata reduce the amount of information processing required to interpret and create meaning from one's environment, nevertheless they are also subject to distortions and biases (e.g. Henderson, Orbell, & Hagger, 2009), and allow for various interpretations and attributions to be made during the process of symptom perception. For example, fatigue and body aches could be attributed to somatic illness, as a symptom of the flu, a sign of emotional distress (e.g. depression) or as a response to environmental stressors, such that these are interpreted as bodily responses to overworking and exhaustion from the work place. Therefore, whether or not a symptom is experienced as physical or psychological is determined by the attribution given to a particular somatic sensation. In contrast, Watson and Pennebaker (1989) suggest that a mind-body Cartesian dichotomy of symptom perception must be abandoned to accept that psychological and physical symptoms are inseparable in the experience of psychosomatic distress.

The symptom-perception model provides a broad approach to conceptualising the symptom perception process and provides insights into the effects of perceptual processes on the interpretation and appraisal of symptoms, whereby symptom perception is a product of somatic cuing, environmental and psychological influences (Gijsbers van Wijk & Kolk, 1997). The broad nature of the symptom-perception model allows for its use to be adapted to respond to a variety of health threats and has been used to explain the perception of symptoms for both common medical symptoms and medically unexplained symptoms (Kolk et al., 2002, 2003).

Nevertheless, despite the symptom perception model's claim to include psychological, biological and environmental influences to perception, the model remains almost entirely psychological. For example, the variable of *external information* is underdeveloped in the model and without description of external influences on a symptom. Furthermore, the symptom perception model contributes very little to the attributional stages of help-seeking (e.g. labelling a symptom), but does recognise differences in how individuals come to notice a symptom. However, a strong emphasis in this model is on attention as it describes the early processes of the appraisal stage, which we now know is the stage accountable for the greatest delay. While the symptom perception model presents an intrapsychic understanding of recognising potential somatic information, it does not adequately place the person in a relationship with their social context nor does it describe the influences of previous health experiences on the perception of somatic information. Therefore it is important to build an understanding of the psychological, social, environmental and biological factors that *all* play a role in the perception and interpretation of symptoms. In the following sections we will review common theories for understanding the processes that occur between symptom perception and seeking medical help and will describe key factors that influence the processes discussed.

Social cognitive theory. Social cognition theory forms an underlying framework for understanding the succeeding decisional processes toward volitional health behaviours, and contributes to the understanding of an individual's response to their physiology, as well as describing how cognitive, affective, situational and social factors contribute to health and illness behaviours (Bandura, 1998; Gijsbers, van Wijk, & Kolk, 1997). Furthermore, it provides a framework for understanding the processes required for an individual to decide or be motivated to seek help and take action.

This process of decision into action is informed by the concept of *self-regulation,* a key concept of the social cognition theory of health behaviour, it describes the importance of goal setting, and striving to achieve a goal that ensures that one is behaving in accordance with one's values, self-perceptions and personal goals (Fiske & Taylor, 1991; Mischel, Cantor, & Feldman, 1996). This process involves three key cognitive processes of clear goal-setting, being motivated to achieve this goal as an "active agent" who determines his or her own behaviour, and taking volitional action to achieve their goals (de Ridder & de Wit, 2006; Gollwitzer, 1993). This dynamic process acknowledges challenges that one may face in achieving a goal, therefore the process allows for continuous evaluation of progress and goal re-formulation to achieve and maintain an important health behaviour in a changing environment (Abraham, Norman, & Conner, 2000; Gollwitzer, 1993; de Ridder, & de Wit, 2006).

Many social cognition models elucidate how health decisions are arrived upon and describe the processes that enable decisions to be translated into action. Some examples of continuous (non-stage model) theories and models include: *the Health Belief Model* (Rosenstock, Strecher, & Becker, 1988), *Social Cognitive Theory* (Bandura, 1986, 1997), the *Theory of Reasoned Action* (Fishbein & Ajzen 1975), *Theory of Planned Behaviour* (Ajzen & Fishbein, 1980; Ajzen, 1991), *Leventhal's model of Self-Regulation* (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steel, 1984), *Protection Motivation* (Rogers, 1983), *Health Action Process Approach* (Schwarzer, 2008) and *Implementation Intentions* (Gollwitzer, 1999). These models are considered social cognition models, given that they describe cognitive and affective (i.e. beliefs and attitudes) factors as primary determinants of health behaviour and acknowledge secondary factors of social, structural, cultural and personality as either primarily or completely mediated by these manipulatable cognitive and affective factors (Sutton, 2004). The health belief model, theory of reasoned action and social cognitive theory have all been successfully implemented into interventions, however, the predictive power of these models have not yet been validated (Glanz & Bishop, 2010; Ogden, 2003).

Social cognitive models differ by the factors described, and their assumptions, or focus on behavioural processes (i.e. appraisal, decision, behavioural stages). Nevertheless, they share the same basic assumptions as the social cognitive theory and, despite the lack of consensus of terminology within the theories; they are more alike than dissimilar (Sutton, 2004). Scientific testing of social cognitive theories has been met with difficulty given the challenge in comparing benefits of using one theory over another (Noar & Mehrotra, 2011) and due to similar factors being labelled differently and presented as distinctly separate concepts (Sutton, 2004*)*.

Given the myriad of social cognition models available in the literature, two of the most influential models will be discussed here, with a focus on *Leventhal's Self-Regulation Model* (SRM; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Partrick-Miller, & Robitaille, 1997; Leventhal, Brissette, & Leventhal, 2003). The two most common help-seeking theories include the SRM, which identifies a help-related behaviour as a response to a health-threat (i.e. a perceived symptom), and the *Theory of Planned Behaviour* (Ajzen, 1991; Ajzen & Fishbein, 1980) which predicts behaviour by proposing the cognitive factors of intention to perform a behaviour, either increasing or decreasing the likelihood of performing a behaviour (de Nooijer, 2002a). In both models, the help-seeking process begins with the perception of a health threat (i.e. symptom).

The theory of planned behaviour (Ajzen & Fishbein, 1980) was derived from the theory of reasoned action (Fishbein & Ajzen 1975), proposing that a person's intention to perform any behaviour can be predicted by three main factors (i.e. individual attitudes toward a behaviour), subjective norms (i.e. whether or not others believe the behaviour should be performed), and perceived control in one's ability to perform a behaviour (Ajzen, 1991; Ajzen & Fishbein, 1980). The theory further claims that behavioural intention is the strongest predictor of behaviour (de Nooijer et al., 2002a). In contrast to the self-regulation theory, the theory of planned behaviour focuses on the behaviour (i.e. procedural response) as opposed to the initial health-threat and posits specific factors that determine a given behaviour. The theory of planned behaviour asserts that the likelihood of engaging in a particular behaviour is determined by evaluating the behaviour (i.e. is this something I *want* to do?), and the assumed barriers to performing the behaviour (i.e. am I *able* to do this?). The appraisal forms the outcome of this evaluation, which includes the subjective norms about the behaviour, effectiveness and expected consequences.

In research, interventions attempt to change an individual's intention to seek medical help by focusing on individual psychosocial factors. Perceived behavioural control has been associated with Bandura's (1997) social cognitive theory construct of *self-efficacy,* in that an individual's belief in their ability to perform a behaviour, and their perceived behavioural control predict the behavioural outcome (Ajzen, 1991). This model has applications in cancer prevention by incorporating concepts of anticipated regret and moral obligation, which are also involved in help-seeking intentions and behaviour (O'Mahony & Hegarty, 2009). Authors of the de Nooijer et al. (2003) study reported that providing knowledge of cancer symptoms, discussing potential barriers, and emphasising the moral obligation to seek help may incite intentions to seek help and avoid feelings of regret which are associated with help avoidance behaviour. These additional social cognitive components may affect an individual's decision to seek medical help rather than seeking the help of a friend (i.e. lay adviser), which may also suggest public attitudes about healthcare services and illness beliefs in general (Burgess, Bish, Hunter, Salkovskis, Michell, Whelehan & Ramirez, 2008;

Rosenstock, 1965). The process of identifying and labelling an individual's symptom(s) is not addressed within the theory of planned behaviour, which is reported by Hunter, Grunfeld, & Ramirez (2003) as the strongest predictor of behaviour. Furthermore, the emphasis on intention as the primary predictor of behaviour is not consistently supported in reality, given that rational decision-making is not always the method used when responding to a symptom or illness (Coiffi, 1991). Sheeran (2002) identified this concept as the *intention behaviour gap* in a meta-analysis investigating the relationship between intentions and behaviour within this model. Findings suggested only 28% of the variance in behaviour was explained by intentions, identifying a key issue in the use of this model. This concept is now commonly termed the *intention-behaviour gap,* and is one of the most significant problems of this model.

The theory of planned behaviour provides a general understanding of factors that influence help-seeking (individual attitudes toward a behaviour, subjective norms and perceived behavioural control), nevertheless this theory is by no means complete and should include the influence of cognitive-perceptual factors in predicting help-seeking behaviour (Coiffi, 1991). Gollwitzer (1999) suggested the implementation of a self-regulatory concept of goal setting (i.e. implementation intentions) to bridge the intention-behaviour gap. De Ridder and de Wit (2006) posit that the self-regulation model is the most complete and appropriate solution to the gap, given that it acknowledges the inconsistencies between an individual's identified health goals and their failure to strive toward such goals (Baumeister & Heatherton, 1996). Health behaviour research can benefit from a self-regulation approach, of which the primary task is to engage in a dynamic process of long-term goal striving, while working to control one's immediate needs to meet the set goal (Mischel, Cantor, & Feldman, 1996; de Ridder & de Wit, 2006). Furthermore, the SRM accounts for the perception and appraisal of symptoms from the moment they are experienced.

Leventhal's self-regulation model. The Self-Regulation Model of Illness Cognition and Behaviour (SRM), also known as the Common Sense Model of Self Regulation, is one of the most widely used models of illness perception and behaviour (Leventhal et al., 1997; Leventhal, Brissette, & Leventhal, 2003). The SRM was a result of Leventhal's prior work on the impact of fear messages in health communications on positive health behaviour (e.g. wearing seatbelts; Leventhal, 1970). The SRM works as a dynamic volitional process in accordance with the self-regulation theory discussed in the previous section. It follows an adaptive system whereby psychological and behavioural responses to a faced health threat (i.e. coping responses) are guided by one's cognitive representation of danger (i.e. illness representations) and emotional representations of danger (which function independently in parallel process; Nerenz & Leventhal, 1983). See Figure 2.3 for a diagram presentation of the model. Illness representations are a key construct of the SRM that builds an understanding of the cognitions associated with the recognition of a health threat (Wearden & Bundy, 2010; Cameron & Moss-Morris, 2010; Leventhal, Brissette, & Leventhal, 2003). An individual's illness representations guide action planning, and both are necessary to produce a behavioural outcome. Therefore, it is a parallel cognitive-processing model of how people cope and actively regulate the response *to* illness danger (i.e. identifying the health threat and asking, 'what can I do about this?'). It further regulates a response of *emotional control* (i.e. acknowledging how they feel and asking, 'what can I do to make myself feel better about this?'). Coping responses are further guided by appraisal heuristics, which assume rules about the way in which symptoms are interpreted, thereby affecting decisions regarding the perceived need to seek medical care (Hale, Therharne, & Kitas, 2007; Scott et al., 2013). Heuristics form the development of an individual's representations of illness (Scott et al., 2013).

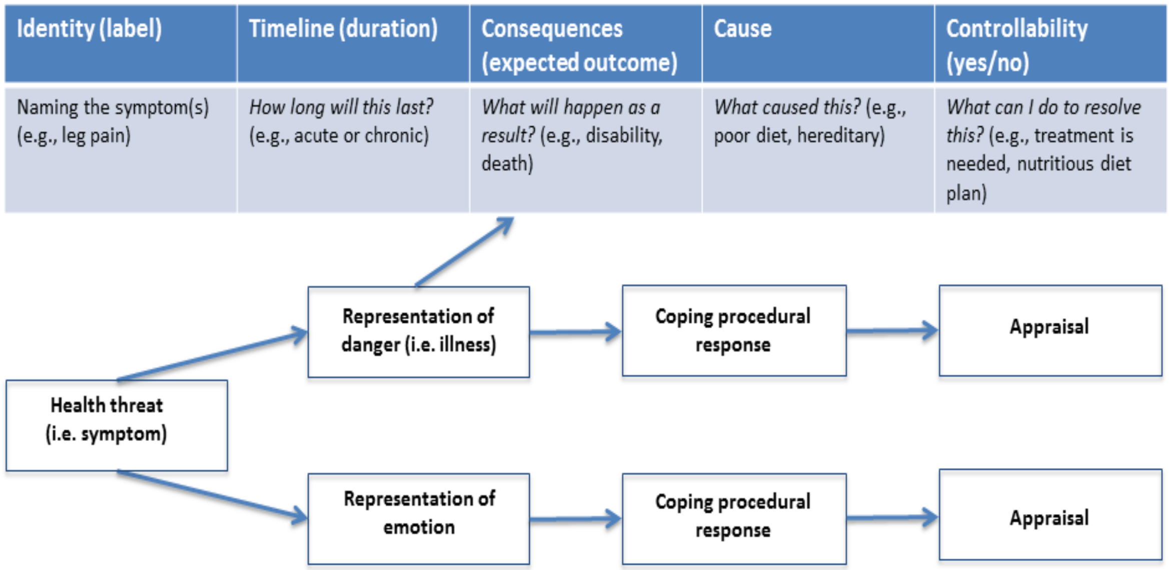

Figure 2.3. The Self- regulation Model**.** Adapted from Leventhal, Brissette & Leventhal (2003, p.46 & p.50).

The five illness representations integrate within an individual's existing schemata (i.e. normative beliefs and understandings), enabling one to make sense of their somatic and biological symptoms, thus guiding behaviour (i.e. coping responses; Cameron & Moss-Morris, 2010; Hale, Treharne, & Kitas, 2007). Illness beliefs include: (a) *Identity*: Illness label or diagnosis that is associated with beliefs about a presenting symptom (e.g. stress, cancer or the flu); (b) *Cause*: Cause(s) of illness that are developed to make sense of a symptom and includes beliefs of controllability (e.g. hereditary factors, stress, diet, exercise); (c) *Timeline*: Expected duration of illness identified in time models of acute, cyclic or chronic and is shaped by experience and knowledge of an illness; (d) *Consequences*: The impact of an illness on physiological, psychological, social and economic aspects of daily life; (e) *Control/Cure*: The ability to self-manage an illness and the belief that the illness is curable or incurable through treatment. Evidence suggests that inaccurate labelling of symptoms (i.e.

identity representations) can lead to increased delay in seeking medical care (Cameron, Leventhal, & Leventhal, 1993; Dracup, Moser, Eisenberg, Meischke, Alonzo, & Braslow, 1995; Scott, 2010). A study by Sissons Joshi (1995) showed how causal representations of illness shape illness beliefs by reporting that 33% of individuals who were diagnosed with diabetes believed that understanding the causes of their illness was unhelpful. This suggests individuals may have believed that their illness was due to uncontrollable causes (e.g. hereditary). The SRM is an exceptionally appropriate model to apply across cultures, given that illness beliefs are experienced globally and can be assessed by the Illness Perceptions Questionnaire (IPQ & IPQ-R; Moss-Morris, Weinman, Horne, Cameron, & Buick, 2002). However, due to the experiential and contextual nature of illness beliefs, cognitions and behaviours are primarily defined by an individual's social world and culture, thus the specific health-beliefs may differ across cultures (Baumann, 2003; Adams & Salter, 2007). Leventhal's SRM framework describes the behavioural, cognitive and emotional responses (e.g. fear or anxiety) that are generated in this parallel process to regulate an experienced threat of illness and consequently influence an individual's health behaviour, and allows one to understand the many different ways in which individuals seek help when they are not seeking help from HCPs (e.g. self-medicating with over-the-counter pain relievers, diet change, consulting a friend or family member).

The SRM has been employed to identify barriers to help-seeking for cancer (e.g. Hubbard et al., 2014; Scott, McGurk, & Grunfeld, 2007) and to identify the psychological processes and heuristics involved in choosing to seek medical help for cancer symptoms (Facione, 2002). The SRM provides an effective theoretical framework from which to build an understanding of the various illness-related beliefs that affect help-seeking behaviour. Furthermore, this model provides room to consider the differences in illness experience amongst diverse cultures of the world (Cameron & Morris, 2010). Unlike the previously discussed stage models this model provides a dynamic framework for understanding help-seeking that allows for continuous re-appraisal of new and existing information and changes to be made to coping responses. Therefore, the SRM adds considerably to the Symptom Perception Model (Gijsbers van Wijk & Kolk, 1997; Kolk et al., 2003) by following the process through to the appraisal of symptom(s), making the decision to seek help, and taking action toward medical help seeking.

This Chapter presented sections according to Andersen's road map and has discussed the symptom perception and appraisal stages through discussion of key help-seeking theories (Figure 2.4). The following sections will present additional psychological factors that influence each stage of the help-seeking process, beginning with the stages discussed, and will then continue to discuss the following processes according to the roadmap (i.e. making the decision to seek help, acting on the decision to seek help, and attending the first appointment with a HCP).

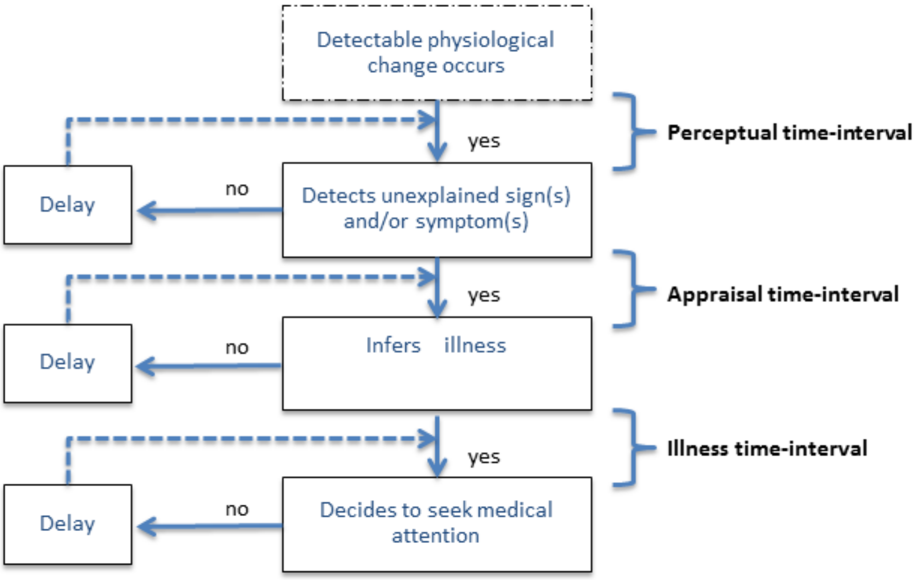

Figure 2.4. Andersen's roadmap discussed thus far. Adapted from The General Model of Total Patient Delay proposed by Andersen, Cacioppo, and Roberts (1995).

Symptom perception and appraisal. Andersen, Cacioppo and Roberts (1995) posited key psychological principles of symptom perception and appraisal (Andersen, Cacioppo, & Roberts, 1995; Cacioppo et al., 1986), suggesting that all individuals are motivated to understand the symptoms they experience, and that one's knowledge of symptoms and/or illness influences the experience of a particular symptom (see Cacioppo, Andersen, Turnquist, & Tassinary, 1989). Therefore, one's knowledge (i.e. illness schemata) is used to determine which symptoms are associated with illnesses. Individuals are often inclined to attach a non-threatening explanation to a symptom experienced (known as the concept of *optimistic bias)*. Optimistic bias acts to prevent chronic negative worry, creating a lack of concern that can increase delayed presentation to healthcare. The final principle posits that symptoms have consequences that affect health and salience of symptoms. These principles work together to influence the psychophysiological comparison process that supports a generally positive view of a person’s physiological condition (Andersen, Cacioppo, & Roberts, 1995)

Cacioppo and colleagues (1986) further acknowledge that when bodily changes do not exceed a *threshold of interference* (i.e. are not salient), they are normalised and dismissed, thus saving cognitive energy by not appraising every bodily change as it occurs. This enables bodily functioning to continue undisturbed (Bradley, Calvert, Pitts, & Redman, 2001). Unforeseen bodily changes, or those that exceed the threshold of interference, are experienced as abnormal and are therefore labelled as symptoms. Alonzo (1979, 1984) refers to this when describing a similar concept, whereby individuals strive for social equilibrium through a *containment* of daily health issues, which are directed by social and life expectations and responsibilities. Alonzo (1979) posits that bodily sensations and illness do not emerge in isolation, but rather are embedded in an individual’s daily social context. The containment concept describes a relationship with one’s social world, whereby it is not until signs and symptoms cause disequilibrium within this framework that an individual may be motivated to seek help (Alonzo, 1984).

The perception of symptoms involves constant monitoring of bodily sensations, which functions in a feedback loop enabling the development of an overall picture of one’s health and illness. Once symptoms are perceived, memories are recalled through an active memory search to enable comparison between the experiencing symptom and an individual’s illness schemata (Leventhal et al., 1997). This provides meaning (i.e. appraisal) to a symptom through activation of illness schemata (Cacioppo et al., 1986). Illness schemata are employed to set a plan for the implementation of coping strategies (e.g. symptom monitoring, self-medicating or medical help-seeking; Leventhal, Brissette & Leventhal, 2003). The impact of this comparison discrepancy, between the actual experience of the symptom and the prior symptom expectation, is portrayed through the example of individuals experiencing myocardial infarction (i.e. heart attack; Perry, Petrie, Ellis, Horne, & Moss-Morris, 2001). In this study, patients held expectations that they would experience sudden symptoms of collapse, dizziness, irregular heartbeat, and loss of consciousness, which did not match with their actual experience of symptoms. The study's findings suggest that both symptom perception and appraisal of symptoms are influenced by contextual and situational cues. An example of this can be seen in cases of medical students' disease, which describes the likelihood for medical students to perceive themselves as experiencing symptoms that are under their current study. This is due to the development of new knowledge, creating a new illness schema that instils fear, thereby heightening one's sensitivity to bodily changes (i.e. selective attention*)*.

As specified in the previous sections, the help-seeking processes are influenced by non-physiological factors, such as environmental cuing, attitudes, beliefs and one's sociocultural context. The literature highlights various different factors that influence these processes. Key factors discussed in the following sections include: (a) *Sociocultural and demographic factors* (Bener, Honein, Carter, Da'ar, Miller, & Dunn, 2002; Calnan, 1983; Rosenstock, 1965), (b) *previous health-seeking habits* (e.g. attitudes toward medical help-seeking, present chronic diseases, comorbidities and past prevention behaviours; O'Mahony & Hegarty, 2009; Quine & Rubin, 1997), (c) *emotional disposition* (e.g. anxiety, negative affect, depression; Banks, Beresford, Morrell, Waller, & Watkins, 1975; Barsky, Goodson, Lane, & Cleary, 1988; Kolk et al., 2003; Robbins & Kirmayer, 1991; Watson & Pennebaker, 1989), (d) *illness knowledge and beliefs* (e.g. illness schema, illness representations, comparison of symptom expectations and experience, and disease vulnerability/risk; Bish, Ramirez, Burgess, & Hunter, 2005; Cacioppo et al., 1986; de Nooijer et al., 2001, 2002a, 2002b; Leventhal, Brissette & Leventhal, 2003; Perry, et al., 2001; Sheikh & Ogden, 1998), (e) *fear* (de Nooijer et al., 2001; Leventhal, Brissette, & Leventhal, 2003; Macleod et al., 2009; Safer et al., 1979; Sheikh & Ogden, 1998), (f) *beliefs about medical services* (Cornally & McCarthy, 2011; de Nooijer et al., 2001; Sheikh & Ogden, 1998), and (g) *social influences* (e.g. social support and social capital; Nosarti, Crayford, Roberts, Elias, McKenzie, & David, 2000; O'Mahony, 2001; Rosenstock, 1965; Song & Chang, 2012).

Factors influencing the processes of perception to appraisal. Of the factors listed above, four key factors are presented here with empirical evidence demonstrating their influence on symptom perception and appraisal. St. Claire (2003) describes the difficulty in trying to identify objective bodily signs as separate from subjective symptoms, which veritably work together to influence the interpretation and appraisal of symptoms. Help-seeking behaviour is an outcome of the constant interchange that occurs between an individual's characteristics (i.e. past experiences, life expectations) and *sociocultural* contextual factors (i.e. social and cultural understandings and expectations), which therefore influence symptom perception, interpretation, decision-making and medical help-seeking behaviour (Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010; Saint Arnault, 2009; Unger-Saldana & Infante-Castaneda, 2011). St. Claire (2003) posits that the way one perceives their bodily sensations is embedded in dominant lay cultural assumptions that build knowledge of how a body *should* function, and how it is experienced within a particular culture. This is further supported by sociocultural help-seeking literature (e.g. Alonzo, 1979; Hay, 2008; Zola, 1973). An example of this is demonstrated by empirical studies suggesting a relationship between an individual's sociocultural context and their experience of pain (Bates, 1987; Callister, 2003; Rollman, 1998). Johnson-Umezulike (1999) suggested a correlation between the intensity of pain experienced and ethnicity in a study of elderly

African American and Caucasian participants. The findings showed that African Americans reported a higher pain response than Caucasian participants (Johnson-Umezulike, 1999). A study by Nayak, Shiflett, Eshun and Levine (2000) found a difference in pain tolerance amongst Indian participants residing in the United States and those in East India, wherein the East Indian residents had a higher tolerance to the pain stimulus (i.e. placing one's hand in a bucket of 0-2 degree Celsius water). However, cultural research often fails to distinguish the difference between race, culture and religion, thereby producing results that are biased to a particular population only and may not be generalisable across wider cultural contexts.

Previous health-seeking habits, particularly in individuals with pre-existing comorbidities, may bias both attention to bodily sensations and the appraisal of symptoms (Barsky, Ahern, Bailey, Saintfort, Lui, & Peekna, 2001), suggesting situational and environmental influences on the experience of symptoms.

Emotional disposition is one of the most influential factors of symptom perception and was tested by Pennebaker and Brittingham (1982) in a study which placed young, healthy volunteers into experimental conditions that manipulated physiological and emotional states. Findings showed that participants whose emotional states were manipulated reported inaccurate information relating to their perception of their own heart rate and fatigue. Findings are consistent with investigations that link *anxiety* and negative affect with a heightened attentional focus to bodily sensations (Watson & Pennebaker, 1989), negative appraisal of symptoms (Sensky, Macleod, & Rigby, 1996) and increased symptom reporting (Watson & Pennebaker, 1989). Beecher's (1956) naturalistic observational study investigated the relationship between pain perception and emotional states by studying a sample of soldiers and civilians. Findings suggested that soldiers who sustained severe wounds (i.e. with predictable high levels of pain) requested pain relief (i.e. morphine) 33% of the time, in comparison to civilians with minor wounds (i.e. moderate levels of pain) who requested pain relief 80% of the time. The offered explanation for this difference was explained by the meanings attached to the individuals' injuries, such that civilians perceived their wounds to represent a negative, detrimental, event in their life, and soldiers perceived this as a 'ticket to safety', which removed them from the negative and highly stressful experience of war. Key findings of this study indicated that an individual's social context and associated emotions moderate the experience of pain, and that pain is not always indicative of symptom severity. The latter finding is supported in the case of experiencing cancer symptoms, wherein early signs of illness does not indicate severity sufficient to warrant the decision to seek medical attention (i.e. often lacking symptom salience and pain), which may account for the increased delay in the appraisal stage for individual's experiencing symptoms of cancer (Melzack & Wall, 1988).

Factors influencing processes of symptom appraisal to the decision to seek help. The accurate perception of symptoms is crucial to facilitate the subsequent appraisal processes and guide the decision and action toward help-seeking (St. Claire, 2003). One's *illness knowledge and beliefs* (i.e. illness schemata) play a key role in facilitating the interpretation of symptoms and the decisions to seek help. As described earlier, help-seeking is only one possible response to the experience of symptoms. For example, an individual may decide to self-manage by self-medicating, monitoring symptoms, initiating life-style changes, and seeking lay advice. Individuals whose symptoms are severe enough to merit medical help-seeking often do not present to medical care (Last, 1963) and symptoms of cancer represent the greatest delay in the appraisal processes. In the Andersen et al. (1995) study of appraisal delay, focus was directed specifically on the distinct symptoms of gynaecological cancer (e.g. bleeding, pain, open sores and lumps), and although symptoms were clearly salient and painful they were not appraised with sufficient severity to seek medical help in 60% of the women sampled. This is likely due to incorrect symptom labelling (i.e. identity), which is driven by one's illness-schema.

Symptom perception (i.e. detection) and appraisal processes are therefore suggested to be subject to many influences, biases and distortions that employ the use of schemata to selectively search out evidence to confirm the label chosen (Pennebaker & Skelton, 1981). The initial label is likely to be confirmed as a result of this biased perception of symptoms. For example: If after many weeks of working long hours at a job an individual begins to feel body aches, this may prompt a search for confirming evidence (e.g. fatigue and tiredness behind the eyes). The body aches may otherwise be interpreted into a new symptom set and labelled as such (e.g. flu) and will then be accompanied by additional symptoms (e.g. sore, throat, sweats and headache) that act as confirmatory evidence for this label. Anderson and Pennebaker (1980) presented evidence for this process by placing individuals into different experimental conditions, subjecting each group to identical sensory inputs (i.e. vibrating Emory board placed on the middle finger). Each participant was primed to receive different expectations about the sensation prior to the stimulus input (i.e. painful or pleasurable and no description was given to the control group). Results showed that participants rated the sensation in accordance with the given expectation, therefore those in the pain group experienced the sensation as painful, the pleasure group experienced pleasure and the control group experienced a neutral sensation respectively. Findings suggested that subtle manipulations of expectations (i.e. schemata) influence the quality of an experienced bodily sensation and subsequent appraisal, highlighting the subjective experience of symptom perception.

Illness schemata further influences the perception of symptoms and their subsequent appraisal, however illness schemata includes more than just symptoms and labels and as such is described through illness representations. Therefore, for every experience of illness, an individual develops a cognitive schema that enables them to understand and label their symptoms (*identity*), generate expectations for the duration of the illness (*timeline*), the *cause(s)*, the severity of illness (*consequences*) and the effectiveness of treatment options (*controllability*). Other schema-guided influences include the schema of *population prevalence*, which suggests that the more rare the symptom, the more severe the disease and the schema of the *sufferer*, which reduces the likelihood that symptoms will be appraised to a particular illness if the knowledge of symptoms for that illness do not match their experience (Croyle & Jemmott, 1991; Salovey, Rothman, & Rodin, 1998).

Emotional factors also play a role in influencing appraisal, given that the experience of known serious symptoms (e.g. breast lump) may cause initial distress sufficient to motivate help-seeking. Alternatively, an emotionally driven appraisal may form a barrier to help-seeking, whereby the anticipation of the negative consequences cause *fear* in accordance with one's illness schema. An example of this is described in the Sherwin (1996) study, which showed that fear was most present in help-seeking for breast cancer symptoms when individuals had known someone close to them with the disease. Individuals are intrinsically driven to avoid negative emotion and to understand their experience of symptoms (Andersen, Cacioppo, & Roberts, 1995). Emotional avoidance can therefore greatly affect the appraisal of symptoms, resulting in a mislabelling of symptoms that is driven by emotion rather than rational thinking (Andersen et al., 1995; St. Claire, 2003).

The model of pathways to treatment. *The Model of Pathways to Treatment* (Scott et al., 2013; Walter, Webster, Scott, & Emery, 2012) integrates current help-seeking theory and key factors that influence the overall process, thereby creating a model that acts within stages while allowing room for dynamic parallel processing (Walter et al., 2012; Figure 2.5). This model was developed to provide a more detailed description of the events and processes that take place between the detection of a bodily change(s) and the start of treatment. For the purpose of this PhD, this model provides a way of thinking about the processes involved after an individual detects a somatic change to their attendance at their initial appointment with a HCP. Given this, the model will only be discussed in this capacity and stages or processes following attendance to the HCP (e.g. diagnosis, start of treatment) will not be discussed in detail in this chapter.

The model was developed in response to a critique of Andersen's stage model (Walter et al., 2012) and incorporates theories of Symptom Perception (Pennebaker, 1983; Gijsbers van Wijk & Kolk, 1997), Social Cognition Theory (Bandura, 1997) and the SRM (Leventhal, Brissette, & Leventhal, 2003). As such it is a dynamic, cyclical model of pathways allowing for multidirectional movement through the many potential pathways to treatment, and focuses on both the motivators in the process of seeking help as well as the barriers (Scott et al., 2013). The model does not establish distinct starting points in the process, which allows a combination of events to be experienced with one symptom, and the flexibility of the model acknowledges that not all events must be experienced to progress through the process toward treatment (Scott et al., 2013). For example, women who are asymptomatic may detect a symptom as a result of regular screening, where an abnormality was found as a result of a national screening programme. In this context, the woman does not seek help for the symptom. Furthermore, after an individual chooses to seek help for a symptom the HCP may deliver falsely reassuring test results or advise the patient to monitor symptoms and return again when intermittent symptoms return or worsen. This is represented in the model by the dashed lines, process arrows and linked processes (Scott et al., 2013). The model presents events, processes and time intervals, as well as incorporating key factors that shorten or extend the time of each interval.

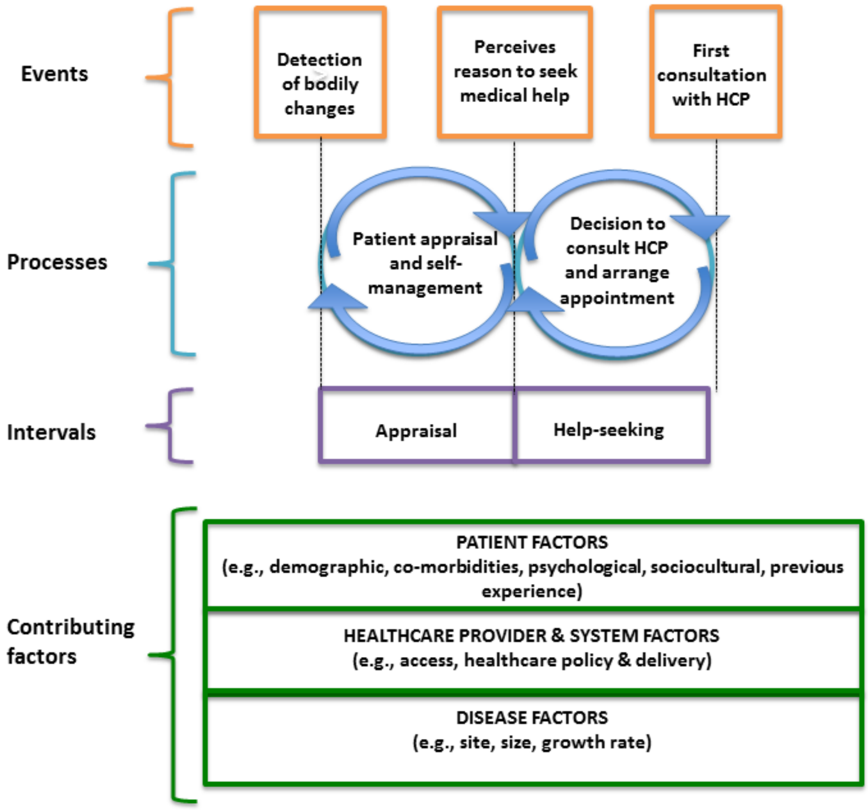

Figure 2.5. The model of pathways to treatment. Adapted from Walter et al. (2012) to include processes to first consultation with a HCP only.

The model of pathways to treatment denotes five events that act as key time points experienced by an individual along their pathway to treatment. As described earlier, the *detection of bodily change(s)* is often known only to the experiencer, and is subject to bias and changes in one's environment. Thus, they may not be indicative of illness. The event, *perceives reason to discuss the symptom with HCP (*'perceives reason to seek medical help' in Figure 2.5.), describes the time point at which an individual perceives that their bodily change(s) are abnormal and this *may* provide reason for an individual to seek medical help. Due to the subjective nature of symptom experience the motivating factor for help-seeking is not a need, but rather a perceived reason to seek help (Bradshaw, 1972). The reasons given for consulting medical care have crossovers with the SRM and include cognitive reasons (i.e. illness representations), consequences (e.g. disruption of daily life caused by symptoms), a perceived inability to cope with symptoms (e.g. failed attempts at self-management) and emotional states (e.g. anxiety, concern or need for reassurance; Scott et al., 2013). Unlike the Andersen's stage model, this model does not assume nor require an attribution of illness for medical help-seeking to take place, given that some symptoms may be detected at regular appointments for screening or comorbidity management (Scott et al., 2013). The combination of the appraisal and illness time intervals provides room for alternate pathways to be undertaken. HCPs define a patient's initial experience of discussing symptoms. If the first consultation is not with a HCP this interaction is considered self-management behaviour and not medical help-seeking.

The events of *diagnosis* and *start of treatment* define the timing of formal medical diagnosis and treatment or palliative management of symptoms. These two events indicate the completion of the diagnostic journey, the end of the *time to presentation interval* and the start of the *time to diagnosis* interval (Scott et al., 2013). Although the focus of this chapter is pre-diagnosis, it should be acknowledged that for many individuals the start of treatment may lead to further symptom appraisal and help-seeking due to side effects and new development that could lead to additional medical consultations or may resolve before the start of treatment (*pre-treatment interval*; Scott et al., 2013). Furthermore, additional events are acknowledged and may occur along the pathway, including booking and attending an appointment with primary care, receiving a referral to specialist care, visiting specialist care, negotiation of treatment plan, and completion of treatment (Bairati, Fillon, Meyer, Her, & Larochelle, 2006; Dang-Tan et al., 2008; Davies, van der Molen, & Cranston, 2007; Evans et al., 2007).

Intervals are defined as time periods between events and include *appraisal* (i.e. between detection to perceiving a *reason* to discuss symptoms with a HCP) *help-seeking* (i.e. between perceiving a reason to discuss with a HCP to first consultation), *diagnostic* (i.e. between first appointment with a HCP and receipt of formal diagnosis) and *pre-treatment* (i.e. between formal diagnosis and start of treatment). The intervals allow for variations within each of the processes.

"Processes are defined as the cognitive, emotional, behavioural, organizational or structural actions that occur within intervals, the outcome of which may lead to the next event" (Scott et al., 2013, p. 51). Processes within the appraisal interval determine responses to bodily change(s) and include the initiation of non-help-seeking behaviours (i.e. self-management). The processes within the help-seeking interval combine the behavioural and scheduling delays discussed in Andersen's model to describe processes that lead to the decision to seek help and the process of planning and arranging appointments. Processes within the diagnostic interval include referrals, several appointments, additional tests or investigations, and for some cancers may involve complex processes of secondary care and defined diagnostic pathways (Walter et al., 2012). If a patient is asked to re-attend when symptoms persist or worsen, the patient will return to the appraisal interval within the model (Evans, Zeibland &McPherson, 2007).

Contributing factors are identified as key factors that influence these processes, timing of events and interval durations. Factors include patient (i.e. individual, sociocultural or contextual factors), HCP and healthcare system (i.e. aspects of health care services that can impact patient and professional decisions and behaviour), and diseases (i.e. clinical and physiological aspects of a condition) factors.

This integrated model of help-seeking is generalisable across symptoms and cancer sites, and there is evidence for its usefulness in the investigation of both short and long appraisal intervals (Walter et al., 2012) with acute and chronic symptoms. This model can also be altered to include disease specific symptoms, diagnostic pathways and alternative pathways to care that could include seeking help from an emergency department, sexual health walk-in clinic, GP service, regular preventative screening appointment, and attendance at regular appointments for comorbidities. The key strength of this model is its distinct intervals with clearly defined start and end points that enable application of this model across research and clinical settings and addresses conceptual criticisms of existing medical help-seeking models (Scott & Walter, 2010).

Making the Decision to Seek Help and Taking Action or Delaying

In previous sections theories for help-seeking were discussed along with detailed descriptions of the processes involved. Factors were presented which influence movement from symptom perception to appraisal. The following sections will discuss the factors which influence how one moves from appraisal to making the decision to seek help, and subsequently taking action toward or away from medical help-seeking.

Often an individual’s experiences with healthcare can influence help-seeking behaviour, as was shown in Koldjeski et al.’s (2005) study, where individuals who experienced ovarian cancer symptoms were misdiagnosed as having benign illnesses on their first contact with healthcare services (i.e. by GPs). It was suggested that this misdiagnosis might have made patients less likely to return, for those who may have believed that returning would waste their time as well as the time of the HCP's (Robb et al., 2009; Smith, Pope, & Botha, 2005). Furthermore, negative attitudes toward consulting a HCP may facilitate delay more than painful or salient symptoms facilitate help-seeking. This is due in part to beliefs about medical services, suggesting that the behaviour of help-seeking will not be effective or that experience of consulting a HCP will be a negative experience (see Chapter 4). Scambler and Scambler (1985) reported that 33% of women consulting a HCP for distressing menstrual symptoms did not believe that treatment would be effective in relieving their symptoms. Additionally, Safer et al. (1979) presented evidence that beliefs about the consequences of illness impacted the help-seeking behaviour, reporting that patients who had imagined negative consequences as a result of their illness, such as imagining themselves on the operating table, took twice as long to seek medical help than individuals who did not have a negative view of the consequences. Findings suggest that for some individuals the decision to seek medical help may take longer to arrive upon, particularly for those experiencing more serious illness, which may be associated with negative treatment consequences (e.g. cancer treatment).

Many patients choose to engage in self-management rather than seeking medical help (Whitaker, Macleod, Winstanley, Scott, & Wardle, 2015). There is evidence to suggest that self-management often plays a key role in increasing time to help-seeking. For example, a study conducted by Mesfin, Newell ,Walley, Gessessew and Madeley (2009) found that patients who self-managed (i.e. seeking alternative medicine and religious forms of treatment) delayed seeking medical care for more days (31 days) than those who did not (15 days). Furthermore, individuals may choose to self-manage, given that this may pose less of an interference with their daily life responsibilities, consequently delaying presentation to healthcare services.

As was described above, individuals employ a myriad of coping strategies, which may not include medical help-seeking. The Protection Motivation Theory (Rogers, 1983) outlines a process for the implementation of coping strategies and responses, as well as the management of a perceived discrepancy between the situational demands and one's ability to meet the demands. The theory outlines processes of appraisal (threat and coping appraisal), which result in the intention to perform adaptive (protective motivation) coping responses to a health threat or maladaptive responses that place the individual at risk to their health (e. g. avoidance and denial; Boer & Seydel, 1995). Four factors are proposed which determine an individual's response behaviour and include: (a) the severity of the threat (e.g. myocardial infarction or death), (b) vulnerability to the threat (e.g. individuals likelihood of experiencing the health threat; Boer & Seydel, 1995), (c) efficacy of the recommended behaviour on reducing the threat (e.g. treatment effectiveness), and (d) an individual's ability to perform the behaviour (i.e. response efficacy and self-efficacy). In a review by Milne, Sheeran & Orbell (2000), authors reported that the protection motivation theory has been used to understand and predict behaviour associated with early detection and threat prevention behaviours (e.g. breast self-examination; Maddux, 1993).

As discussed in the SRM, emotions such as fear can motivate or hinder behavioural responses to a threat (de Nooijer et al., 2001; Macleod et al., 2009; Smith, Pope, & Botha, 2005). Fear is described as an intervening variable that impacts perceptions of severity and vulnerability to a threat appraisal (Boer & Seydel, 1995; Stainback & Rogers, 1983) and the decision to seek help is two-fold, given that individuals experiencing a fear response to a health threat may be motivated to seek medical help to reduce their negative emotional response or may choose to avoid the emotion by choosing not to seek help and appraising the symptom as benign, as described by the theory of planned behaviour (Ajzen & Fishbein, 1980; Ajzen, 1991).

Action Toward Help-seeking Behaviour

Having reached the decision to seek help one might assume that making an appointment and subsequently attending this appointment might follow automatically, especially in a country such as the UK that offers free national healthcare. However, this is not the case as we know from the evidence presented in the first section, with nearly 12% of individuals failing to present to their GPs with significant symptoms that merited medical care (Hardey, 1998). It is reasonable to assume that an even greater proportion of patients fail to convert their decision to seek help into action by contacting medical services to book an appointment. It has been suggested that the "gatekeeping" system of UK healthcare (as described in Chapter 1) may be a structural barrier partially responsible for limiting the help-seeking behaviours of its citizens (see Vedsted & Olesen, 2011; Andersen et al., 2011). However, when we focus on the psychological aspects of help-seeking we become aware of a gap between an individual's intention to seek help and their behaviour. An Orbell and Sheeran (1998) study supported this criticism by reporting that 57% of women, who stated intention to attend cervical screenings a year later, did not re-attend for their scheduled screenings. Further meta-analyses suggest that one's intention only predicts 20-30% of intended behaviour.

Sociodemographic factors are reported in the literature to impact help-seeking behaviour with individuals of a low socioeconomic background being less likely to utilise healthcare services due to an inability to access care (e.g. lack of public transport or affordable parking; Low, Waller, Menon, Jones, Reid, & Simon, 2013a; St. Claire & Turner, 1998). Alternatively one's environment, in particular their social environment, can act as a motivating factor for help-seeking, suggesting that and support networks can encourage medical help-seeking behaviour (Calnan, 1983; Chatwin & Sanders, 2013; Mwaka, Okello, Walinga, & Walter, 2015). However, some social networks increase delay by acting as lay advisers for individuals seeking help, thereby substituting the role of the HCP with often-uninformed advice (Elliot-Binns, 1973).

Integrating Models of Help-seeking

In order to summarise the theoretical information and influential help-seeking factors presented in this review, an integrated model of help-seeking has been developed to create a comprehensive picture of the models, and to place it within the context of gynaecological cancer and the empirical chapters to follow.

A help-seeking study for breast cancer, Hunter, Grunfeld and Ramirez (2003) highlighted the value of employing multiple models in the initial stages of research to incorporate key components of help-seeking models (including the SRM) Furthermore additional factors should be integral into a comprehensive help-seeking model. Such factors should include sociocultural, economic, personal, and healthcare system factors that influence time to help-seeking for women seeking help for gynaecological and other cancers. This suggestion is supported by evidence reported in a recent review by Whitaker, Scott and Wardle (2015) that identified the important impacts of external factors along the many intervals of the help-seeking journey from perception and detection of a symptom to attendance with a HCP. It is therefore important that help-seeking theories include symptom perception processes to build a comprehensive framework from which to gain an understanding of help-seeking for symptoms. In response to the previously identified suggestions for a more integrated and comprehensive help-seeking theory, an integrated model is suggested (Figure 2.6) that incorporates the key elements of each of the three key models employed in the current thesis and influencing factors that impact these dynamic processes. When combined, these models produce a comprehensive model of help-seeking that encompasses the processes of symptom perception, symptom appraisal, selection and monitoring of coping responses (e.g. self-management) as well as making the decision to seek help from a HCP.

Given the complex biopsychosocial influences and the dynamic cognitive processes involved in seeking help for gynaecological cancers, an integrated model is proposed to acknowledge the many influences (both known and unknown) on the journey toward help-seeking for potential symptoms of gynaecological cancers. Given that it is grounded in the Model of Pathways to Treatment framework (Scott et al., 2013; Walter et al., 2012), the integrated model of help-seeking is a generalisable model across different symptoms and cancer sites. Further evidence suggests that it may be useful in the investigation of both short and long appraisal intervals with acute and chronic symptoms of illness (Walter et al., 2012), making it suitable for the various symptoms indicative of gynaecological cancers. This model can also be altered to include disease-specific symptoms, alternative pathways to care and diagnostic pathways (Walter et al., 2012) that could include seeking help from an emergency department, sexual health walk-in clinic, GP service, regular preventative screening appointment and attendance at a regular comorbidity management appointment (e.g. for diabetes or hypertension). Therefore, in the context of gynaecological cancers this model could be used to examine help-seeking for the vague and non-specific symptoms indicative of this cancer type.

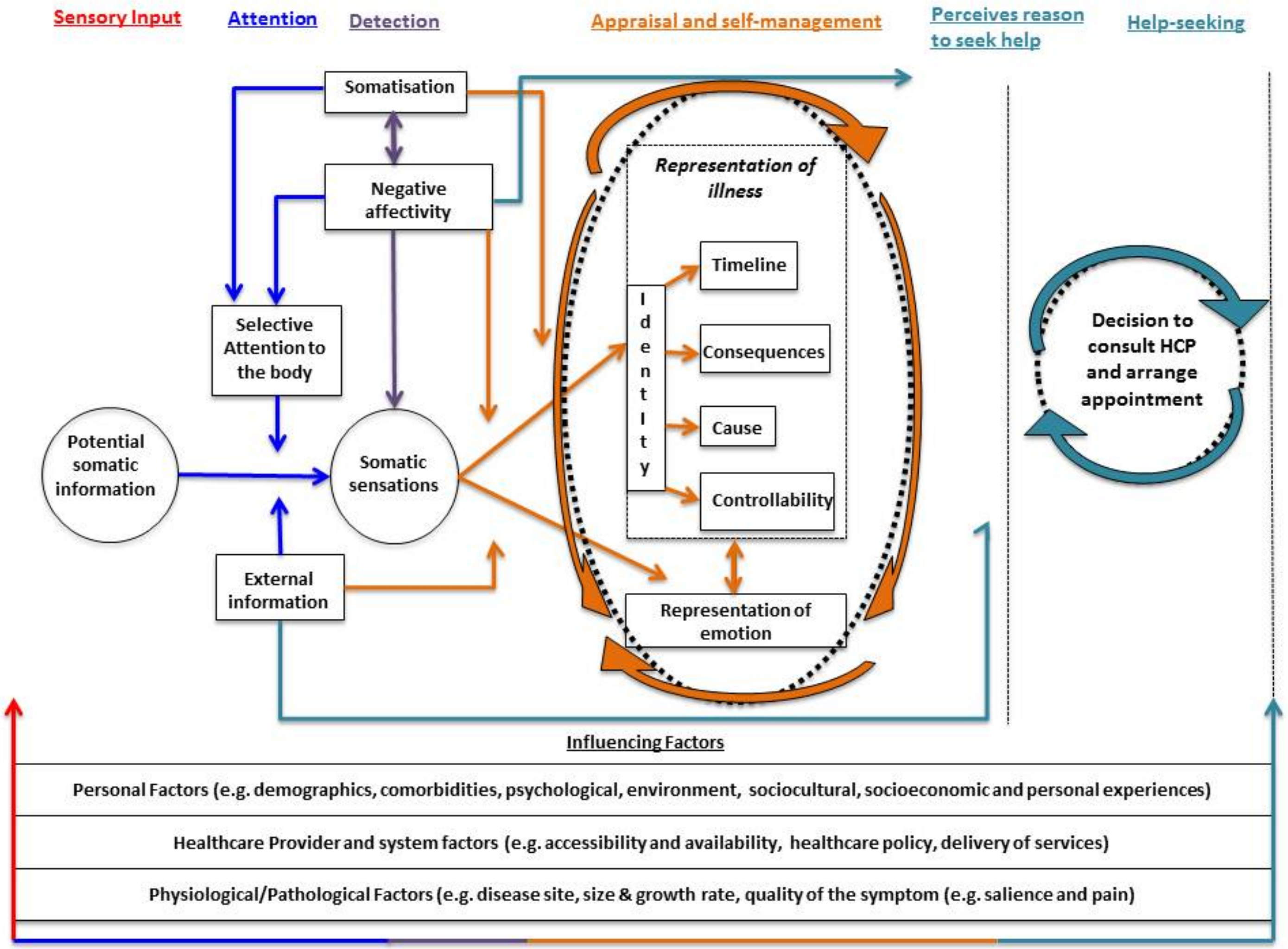

Figure 2.6. Integrated Model of Symptom Perception (Gijsbers van Wijk & Kolk, 1997; Kolk et al., 2003), Leventhal's Self-Regulation (Leventhal, Brissette, & Leventhal, 2003), and the Model of Pathways to Treatment (Scott et al., 2013; Walter et al., 2012).

Conclusions and Moving Forward

Theory enables us to create a framework for understanding how an individual comes to recognise bodily symptoms and form associations with potential illness, thereby influencing help-seeking behaviour. However, more research is needed to understand the barriers to medical help-seeking behaviour. Furthermore, many of the help seeking theories do not account for the role of sociocultural dimensions and the impact of situation and context on medical help-seeking behaviour. Sociocultural dimensions include familial and social context as well as cultural beliefs, norms and experiences. Methodological application of Andersen's stage model is said to apply more comfortably to the Western healthcare system. Nevertheless, due to issues highlighted in this chapter an integration with more dynamic models of SRM (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steel, 1984) and the Model of Pathways to Treatment (Scott, McGurk, & Grunfeld, 2007; Walter et al., 2012) is necessary. Therefore an integration of the models is introduced to gain an understanding of the dynamic cognitive processes that are involved in the experience of appraising a symptom ad coming to the decision to seek medical help, within the context of seeking help for potential symptoms of gynaecological cancer.

A review of the gynaecological cancer and help-seeking literature presented in this thesis is presented in summary in the following chapter to build a foundation for the PhD research and how the proposed studies aim to fill gaps in the literature.

CHAPTER 3: DRAWING CONCLUSIONS OF THE LITERATURE- DIRECTIONS FORWARD

Aims

The purpose of the current chapter is to briefly highlight key findings from the literature reviews into gynaecological cancers and psychological help-seeking theory in Chapters 1 and 2 respectively, and to use this information to present a research plan that detail, with explicit goals, for the remainder of the PhD.

Key Point Summary: Chapter 1

Gynaecological cancers vary by incidence, risk factors, signs and symptoms, treatments and outcomes. Nevertheless, it is clear that these forms of cancer hold a strong worldwide disease burden accounting for approximately a quarter of all diseases in women (Ferlay et al., 2013a). A review of the literature highlighted that the prevalence of gynaecological cancer in women of postmenopausal age is very high, with endometrial cancer reported at the highest incidence rate and ovarian cancer with the highest mortality for developed countries. Common causes and risk factors for the development of gynaecological cancers include post-menopausal age, genetic factors, hormonal imbalance (e.g. caused by HRT, breast cancer treatment, or obesity), infertility, sexually transmitted infection, and common lifestyle factors (e.g. low socioeconomic status, smoking and poor diet). Early stage gynaecological cancers often present with vague or non-specific symptoms, with the exception of endometrial cancer, which primarily presents with a distinct symptom of post-menopausal bleeding (PMB).

The National Institute for Clinical Excellence, clinical guidelines (2005) provide distinct diagnostic pathways for each cancer site, dictating diagnostic practices for gynaecological cancers in the UK. Mortality is regularly determined by the stage of cancer at time of diagnosis, which determines the course and effectiveness of each treatment. Therefore, early detection and prompt help-seeking can significantly improve treatment and survival outcomes for gynaecological cancers.

Key Point Summary: Chapter 2

Understanding what leads women to seek help and what influences the process of delay is essential to inform help-seeking research in this population. Despite the high incidence of gynaecological cancers, some individuals still delay when seeking help, therefore it is important to identify populations at greatest risk of delay. The literature provides an overview of the health behaviour theories for use in applied psychological investigation into help-seeking for symptoms of cancer.

A review of help-seeking theory supports the understanding that medical help-seeking is not an event but a series of stages and processes that include the perception of somatic information, the appraisal of this information, and the associated decision-making processes that determines how one responds to an appraised symptom. Help-seeking theories should include clearly identified contextual, cognitive, emotional and social factors and should lay a framework for dynamic and parallel processes rather than rational decision making points or discrete stages.

The current research is informed by reviewed models of the Symptom Perception Model (Gijsbers van Wijk & Kolk, 1997; Kolk, Hanewald, Schagen, & Gijsbers van Wilk, 2003), the adapted Andersen's General Model of Total Patient Delay (Cacioppo, and Roberts, 1995), the Leventhal's Self-Regulation Model (Leventhal et al., 1997; Leventhal, Brissette, & Leventhal, 2003) and the Model of Pathways to Treatment (Scott, Walter, Webster, Sutton, & Emery, 2013; Walter, Webster, Scott, & Emery, 2012) which, when integrated, produce a more complete theory of help-seeking behaviour from the perception of a symptom to attending an appointment with a healthcare professional (HCP). Additional factors have been identified to influence the help-seeking process and include biopsychosocial and environmental influences of the dynamic process of medical help-seeking.

Moving Forward

Literature suggests that women report weight barriers to healthcare, which may contribute to delay in the utilisation of gynaecological health services. The specific factors that contribute to obese women delaying help-seeking for symptoms of gynaecological cancer have not previously been identified. This research is timely given the increasing relevance of obesity as a public health concern and the strong association with increased risk, morbidity and mortality for a range of different cancers. Although it would be preferable to reduce levels of obesity, the current situation demands a focus on improving help-seeking behaviour amongst obese women to improve survival outcomes. Specific factors that influence delay amongst this patient group have not been studied in the context of gynaecological cancer services, and given the increased risk and morbidity for gynaecological cancers amongst obese women, early detection and prompt help-seeking for women experiencing symptoms of gynaecological cancers should be an important focus for research.

Research Plan

The proposed research will account for limitations inherent in delay research (see Scott & Walter, 2010) through adherence to a theory driven approach, a mixed methods approach that employs a broad sweeping quantitative questionnaire as well as an in-depth qualitative interview study to examine the process of help-seeking for women experiencing symptom(s) of gynaecological cancer (Chapters 5 - 7). See Figure 3.1 to provide an overview of the areas of help-seeking investigated in each empirical chapter.

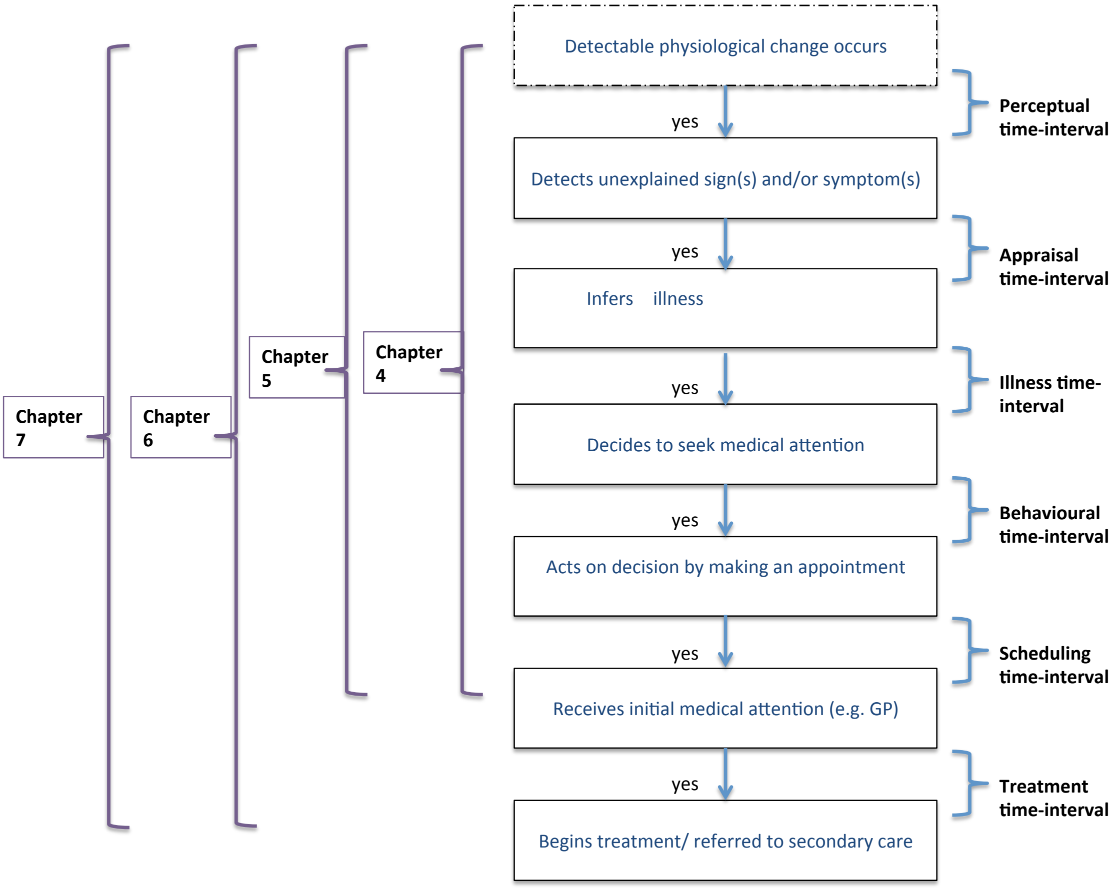

Figure *3.1*. Empirical chapter outline according to help-seeking intervals.

The aims of the thesis are as follows: (a) to explore the health beliefs and help-seeking attitudes of normal weight, overweight and obese women (Chapters 4, 5 & 7), (b) to identify predictors of delay in help-seeking amongst normal weight and overweight/obese women and to acknowledge differences between obese and non-obese women in their time to help-seeking (Chapter 5), (c) to understand the experience and process of help-seeking for obese women (Chapters 6 & 7) and (d) to identify whether differences exist across ethnicities regarding knowledge about gynaecological cancers. As such, the PhD will address the following research questions:

(a) What can we learn about help-seeking from the perspective of HCPs? (Chapter 4)

(b) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ between obese and non-obese women? (Chapters 4 & 5)

(c) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ across different ethnic groups? (Chapters 4 & 5)

(d) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ between women who extend time to help-seeking and those who do not? (Chapter 5)

(e) What are the predictors of delay in help-seeking amongst normal weight, overweight and obese women? (Chapter 5)

(f) Are there differences between obese and non-obese women regarding time to help-seeking? (Chapter 5 & 6)

(g) Are there differences across ethnicities regarding time to help-seeking? (Chapter 6)

(h) What is the experience of an obese woman seeking help for potential symptoms of gynaecological cancers? (Chapter 6 & 7)

These questions were examined in four studies. The development of the questionnaire study reported in Chapters 5 and 6 were informed by comprehensive literature reviews (Chapters 1 & 2) and results of the first study (Chapter 4), which informed the development of measures in Chapter 6 as well as the interview schedule for Chapter 7.

Structure of the following Chapters 4 to 8

Chapter 4: A qualitative analysis of healthcare professionals' beliefs about obese women seeking help for symptoms of gynaecological cancer presents results of a qualitative study with the purpose of exploring HCPs' perspectives about the potential barriers, beliefs and behaviours of help-seeking amongst the obese women that attend their services. Semi-structured interviews were undertaken with 20 HCPs that specialise in gynaecological cancer services (i.e. consultants, nurses, psychologists, radiologists, general practitioners) in Birmingham Women's NHS Foundation Trust and University Hospitals Birmingham NHS Foundation Trust. Data were analysed using the Framework analysis method. The aims of this study were two-fold, (a) to explore HCPs' perspectives on the use of gynaecological services amongst obese patients presenting with symptoms of gynaecological cancers and (b) to explore HCP's beliefs about the potential barriers and motivators that influence help-seeking amongst obese women in their service. Furthermore, Chapter 4 builds a foundation for patient research into the predictors of delay for obese women seeking help for gynaecological symptoms (Chapters 5 and 6).

Chapters 5 and 6 present two separate patient studies that answer research questions from b to g, the patients' perspective. The development of these studies was informed by literature reviews and the results of Chapter 4. *Chapter 5: Predicting help-seeking for symptoms of post-menopausal bleeding,* presents a quantitative study which examined predictors of delay and barriers to help-seeking for symptoms of gynaecological cancer amongst a non-stratified sample of 164 women of variable BMIs (19.5 – 45.10) attending their first appointment at a Sandwell and West Birmingham Hospitals NHS Trust PMB clinic after being referred for a suspicious symptom of cancer (i.e. PMB). The questionnaire examined sociocultural and demographic factors, body image satisfaction, objective body size/body weight, mood, illness perceptions, previous health behaviours, social capital and gynaecological cancer awareness, assessed these factors and how they may be associated with time to help-seeking for symptoms of post-menopausal bleeding. A multiple regression analysis was conducted to identify the predictor(s) of extended time to help-seeking by identifying key variables that predict extended time to help-seeking for women experiencing a potential symptom of gynaecological cancers (i.e. PMB).

Chapter 6: Mapping the help-seeking journey, presents an additional analysis that maps the dynamic process and associated behaviours involved in seeking help for PMB, and compares differences in help-seeking amongst different groups of obese and non-obese women and White-European and British Asian and Minority Ethnic groups in time taken along the journey of help-seeking from detection to PMB referral.

Chapter 7: The lived experiences of obese women seeking help for post-menopausal bleeding- A qualitative IPA study, explores the experience and beliefs (i.e. illness perceptions and body image) of seven obese women (BMI > 35.9) in their journey toward help-seeking for PMB and identifies how women make sense of this experience. Participants were recruited from the questionnaire study and data collection was achieved through an open-ended in-depth qualitative interview. Data was analysed using Interpretative Phenomenological Analysis to explore the meaning of the help-seeking experience amongst obese women.

The final Chapter (*Chapter 8: General discussion*) provides a summary of research findings and a general discussion relating back to the literature to discuss the research limitations, suggest directions for future research and/or interventions, to outline the theoretical and practical implications of the research, and to formulate an overall conclusion for the PhD.

The British Psychological Society guidelines for ethical practice were adhered to in the design and conducting of the research studies that form this thesis. Ethical approval was granted by the appropriate NHS and University Ethical Review Committees and local NHS Research and Development Centres. Please see Appendix A for all ethical approval letters.

CHAPTER 4: A QUALITATIVE ANALYSIS OF HEALTHCARE PROFESSIONALS' BELIEFS ABOUT OBESE WOMEN SEEKING HELP FOR SYMPTOMS OF GYNAECOLOGICAL CANCER

Introduction

Obesity has widely been reported as one of the risk factors for gynaecological cancers (Bhaskaran, Douglas, Forbes, dos-Santos-Silva, Leon, & Smeeth, 2014); Lane, 2008; Reeves, Pirie, Beral, Green, Spencer, & Bull, 2007), namely endometrial (Stevens, Jacobs, Patel, Sun, Gapstur, & McCullough, 2014) and some ovarian cancer sub-types (Olsen et al., 2013). This is a significant issue given that over one quarter of women in the UK and one third of women in the USA are estimated to be overweight or obese (Organisation de Cooperation et de Developpement economiques [OECD], 2014; Stevens et al., 2012). Furthermore, although the relationship between BMI and surviving gynaecological cancers is currently not fully understood, obesity has been found to play an important role in treatment outcomes for some gynaecological cancers (Backes, Nagel, Bussewitz, Donner, Hade, & Salani, 2011; Olsen et al., 2013; Reeves et al., 2007). The survival rate of all gynaecological cancers is dependent upon their stage at the time of diagnosis, highlighting the importance of screening tests, early detection and prompt help-seeking particularly for those who have an increased risk of developing the disease. Nevertheless, the often vague and non-specific symptoms of gynaecological cancers pose a challenge to the appraisal of symptoms as severe enough to require medical help (Koldjeski et al., 2005; Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009; Smith, Pope, & Botha, 2005).

In terms of help-seeking behaviour, obese women have been found to be less likely to attend gynaecological cancer screening tests in comparison to non-obese women, despite being at higher risk of developing gynaecological cancers (Aldrich & Hackley, 2010; Maruthur, Bolen, Brancati, & Clark, 2009). Furthermore, they are more likely to seek healthcare services at a later and more advanced stage of breast and gynaecological cancers (Arndt, Stürmer, Stegmaier, Ziegler, Dhom, & Brenner, 2002; Maruthur et al., 2009). A number of factors have been suggested to facilitate such a delay in help-seeking and presentation of obese women to healthcare services. Such factors include: (a) perceived weight-stigma amongst healthcare professionals (HCPs; Alegria Drury & Louis, 2002; Puhl & Brownell, 2006; Phelan, Burgess, Yeazel, Hellerstedt, Griffin, & van Ryn, 2015; Puhl & Heuer, 2009), (b) embarrassment of one's body during gynaecological examinations (Amy, Aalbord, Lyons, & Keranen, 2005; Ridolfi & Crowther, 2013), (c) lack of symptom and disease knowledge (Soliman et al., 2008), and/or (d) concerns regarding lack of suitable equipment to enable examination of women with larger body sizes (Amy et al., 2005; Uppot, 2007).

HCPs play a key role in influencing patient health behaviour change and help-seeking (Puhl & Heuer, 2009; Jackson, Wardle, Johnson, Finer & Beeken, 2013; Rose, Poynter, Anderson, Noar & Conigliaro, 2013). A review conducted by Rose and colleagues (2013) suggested doctor-patient communication that included weight-loss advice positively influenced patients' weight-loss. A study conducted by Hebl and Xu (2001) reported that clinicians communicated less positively with obese women when compared to women of normal weight, furthermore clinicians often believed that overweight or obese patients were less likely to comply with medical advice (e.g. to lose weight) or benefit from psychological therapies (e.g. counselling for comorbid depression). This is important because studies have shown that when a doctor and patient hold differing opinions about a patient's motivation for weight-loss or health, positive communication regarding positive and preventative healthy lifestyle choices are exceedingly difficult (Befort et al., 2006).

A study on medical help-seeking delay, by Amy and colleagues (2005) found that patients' decisions to delay care was often related to their treatment and to communications with HCPs. Concerns included disrespectful interactions and perceived negative attitudes of HCPs, the anticipation of receiving unsolicited weight-loss advice and a lack of size appropriate equipment available in clinic (i.e. gowns, examination tables and equipment). A study exploring the barriers and facilitators of help-seeking for breast and cervical cancers paralleled findings from the previously mentioned study, however they also found that women believed that having positive and trusting relationships with their General Practitioners (GPs) facilitated help-seeking (Marlow, McGregor, Nazroo, & Wardle, 2014).

To date, minimal research has focused on the experiences of HCPs working with obese women in gynaecological cancer services. An exploration thereof would further our understanding of this patient group's delayed help-seeking behaviours, given that HCPs have direct experience of working with this client group and are well-placed to provide insight into healthcare service barriers and factors that impact the utilisation of services. Although factors have been suggested in the literature to describe obese-specific influences that may act as barriers to general medical help-seeking, specific factors have not been studied in the context of gynaecological cancer services. Given the increased risks for disease and poorer outcomes for gynaecological cancers amongst obese women, early detection and prompt help-seeking for women experiencing symptoms of gynaecological cancers should be an important focus for research. Therefore, the aims of this study are: (a) to explore HCPs' perspectives on the use of gynaecological services amongst obese patients presenting with symptoms of gynaecological cancers; (b) to explore HCPs' beliefs about the potential barriers and motivators that influence help-seeking amongst obese women presenting with symptoms of gynaecological cancers; (c) to provide suggestions that inform the development of interventions to encourage prompt help-seeking behaviours in this patient group. The findings of this study build the foundation for the following studies (Chapters 6-8), which investigate predicting factors and processes of help-seeking behaviour in obese women with potential symptoms of gynaecological cancers.

Methods

Context

The study was sponsored by the University of Birmingham under the Research Governance Framework and received ethical approval from the Science, Technology, Engineering and Mathematics Ethical Review Committee at the University of Birmingham (Reference number: ERN_12-1420) and the Birmingham Women's Hospital NHS Foundation Trust (Reference number: 13/BWH/NO89). See ethical approval letters in Appendix A.

Sample and recruitment

HCPs were identified for recruitment by the researcher (S. T.) through Internet searches of hospital gynaecologic and oncology consultants and potential participants were selected based on their working in direct contact with obese women in gynaecology and gynaecology oncology (gynae-oncology) services across four hospital sites (City Hospital, Birmingham Women's Hospital, Sandwell Hospital and Queen Elizabeth Hospital)[1]. Consultants and clinic managers further identified other members of the cancer support team (i.e. radiographer, psychologist, nurses). A convenience sampling technique was employed and participants who met the above criteria of current employment as a HCP in gynaecological cancer care services, and who were in weekly clinical contact with patients,

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[1] City, Women's, Sandwell and Queen Elizabeth Hospitals are the four major NHS hospitals that provide gynae-oncology services to Birmingham.

were contacted by the researcher via letter or email providing information about the study and inviting them to participate in an interview exploring HCPs' perspectives on obesity and gynaecological cancers (see Appendix B & C for cover letter & information sheet for participants). Interested participants agreed to participate by emailing the researcher to arrange an interview date in their place of work. The sample consisted of HCPs working in the professional contexts of nursing, oncology, general practice, and other members of the direct care team (i.e. clinical psychologist, radiologist).

Participants

Thirty HCPs were identified as suitable participants. Twenty participants agreed to take part in the study (response rate 71%). Of the 20 participants, 8 were male and 12 were female. Their ages ranged from 30 to 68 years (M = 45; SD = 2.5). Fifty-five per cent (n= 11) of the participants were of a white ethnic origin, and 5% (n=1) black ethnic origin. Descriptive statistics are presented in Table 4.1.

Table 4.1.

HCP's Descriptive Statistics

Sociodemographic characteristics of sample	N(n=20)	%
Age		
<40 yrs	5	25
40- 49 yrs	8	40
<50 yrs	7	35
Gender		
Male	8	40
Female	12	60
Race/ethnicity		
White/ White British	11	55
Black/ Black British	1	5
South Asian/ Asian British	3	15
Chinese/ other Asian ethnic grps	2	10
Mixed Race/Other	3	15
Professional Role		
Gynaecologic consultant	2	10
Gynaecologic oncology consultant/surgeon	5	25
Specialist gynaecology nurse	1	5
Gynaecologic oncology advanced nurse practitioner/certified nurse specialist	5	25
General Practitioner	2	10
Gynaecologic oncology staff nurse	2	10
Other: Member of cancer care team (i.e. clinical psychologist, registrar, radiographer)	3	15
Education/Job Relevant Qualification		
General Nursing	4	20
Certified Nurse Specialist	2	10
Masters Level/Postgraduate	4	20
Medical Degree & Further Specialist qualification	10	50
Years Since Qualification	Mean 9; Range (2-26)	

Interview Schedule and Procedure

A semi-structured interview schedule was developed through a literature review (Chapters 1 and 2) and through discussions with clinical, health and research psychologists working at the University of Birmingham and in the Sandwell and West Birmingham Hospitals NHS Trust. The interview schedule was piloted in an interview with a clinical psychologist working in gynaecological cancer care at one of the approved sites. Minor changes were incorporated into the interview schedule as a result of the pilot interview, whereby questions were reordered to facilitate clarity and ensure a conversational format. Questions in the interview schedule addressed the main aims of the present study (described on pages 3 - 4) (see Appendix D for the interview schedule). Participants were encouraged to share their opinions and experiences of working with obese women in gynaecological services. Question topics addressed the experiences of working with overweight or obese patients, clinical challenges specific to obese patients, such as advising patients to lose weight, and perceptions of gynaecological cancer awareness (i.e. risks & symptoms) amongst this group. They also addressed beliefs about the patient process of seeking help, including attitudes towards vaginal examination and interpretations of perceived barriers to patient care.

Prior to the commencement of the interview all participants were provided with a paper copy of the study information sheet and were given the opportunity to ask questions. Written consent was then acquired. Interviews were conducted face-to-face (from January to September, 2013) and ranged from 15 to 61 minutes (mean 37 minutes). Interviews were recorded and transcribed verbatim.

Data Analysis

Data were analysed using the 'Framework' method (Ritchie & Lewis, 2003), which is a common qualitative method used in applied health and social policy research in the UK (Patel, Ferner, & Grunfeld, 2011). Framework analysis does not follow one epistemological stance, but aims to holistically explore an individual's subjective understandings of their experience within their social world (Ward, Furber, Tierney, & Swallow, 2013). The development of a thematic framework provides a systematic method of synthesising interview data to compare data across and within individual cases (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Framework analysis allows for an integration of both inductive and deductive theme development whereby the themes are selected to specifically answer research questions. Therefore, framework analysis was selected as the ideal methodology to for an exploratory study into the experiences of HCPs in their interactions with obese patients, and their perceptual realm beliefs about delay amongst this group. This study also aims to identify potential barriers and motivators of help-seeking from the perspective of the healthcare professionals as a means of informing practice. See Table 4.2 for study aims and research questions.

Table 4.2.

Study Aims and Research Questions

	Specific aims for the HCP interview study	**Research questions that address each aim**
1	To explore HCPs' perspectives on the use of gynaecological services amongst obese patients presenting with symptoms of gynaecological cancers.	What are HCP's perceptions of obese women's use of gynaecological cancer services?
2	To explore HCPs' beliefs about the potential barriers and motivators that influence help-seeking amongst obese women presenting with symptoms of gynaecological cancers.	What are the HCPs' beliefs about the barriers and motivators for help-seeking amongst obese women with symptoms of gynaecological cancers?
3	To provide suggestions to inform interventions developed around encouraging earlier help-seeking behaviours in this patient group.	What interventions may be developed to encourage obese women to seek help sooner?

A five-step process of analysis was followed: (a) Data immersion, (b) coding and thematic framework development, (c) indexing and charting, (d) summarising data in an analytical framework, and finally (e) synthesising the data with interpretation.

Step 1: Data immersion. The researcher read each transcript and made notes of her reflections, thoughts and general impressions. The first three transcripts were reviewed by the researcher's supervisors (M. L., E. G. & R. H.) to ensure that the data were of high descriptive quality, and that each research question was answered.

Step 2: Coding and thematic framework development. A process of ‘open coding’ was conducted on half of the interviews using NVIVO software (QSR International, Version 10) to paraphrase or label sections of each transcript that could potentially answer one or more of the research questions. A working index was then created using the coding structure developed in the previous step, which represented working themes and sub-themes according to specific research questions.

Step 3: Indexing and charting into the framework matrix. The index was then applied back to the complete dataset to work as a structured thematic framework for the rest of the data analysis. A framework matrix was created to chart the data into themes for each participant.

Step 4: Summarising and organising the existing framework. In this step each case was summarised using key themes and a more concise framework was created to detail themes and subthemes that specifically met the research aims across cases. Subsequently, 15% (n = 6) of the cases were analysed independently by a second researcher (L. A.) to determine agreement in interpretation of the data.[2] Differences in theme titles were resolved through discussion with research supervisors, resulting in the name of a theme being changed from ‘negative judgments received from HCPs’ to ‘perceived HCP negative attitudes about obesity’ to avoid exaggerated interpretation of participants’ narrative. Furthermore this theme was combined with low body-esteem due to the association revealed between body image and perceived HCP’s negative attitudes of obesity.

Step 5: Synthesising the data with interpretation. The data was then reviewed and synthesised to map connections between themes and clearly describe the experiences and beliefs of HCPs working with obese women in gynaecological cancer care.

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[2] Inter-rater reliability co-efficient is inappropriate to report for this type of qualitative data due to lack of empirical support for its use (Armstrong, Gosling, Weinman & Marteau, 1997).

Results

A total of seven superordinate themes emerged to describe (a) *the perceptions of HCPs about obese women in gynaecology services* and (b) *the perceived barriers and motivators for help-seeking amongst obese women with symptoms of gynaecological cancers.* Additionally, HCPs provided insight into potential interventions for improving help-seeking amongst this group. Superordinate themes and subthemes are described in the two sections below.

HCP perceptions about obese women in gynaecology services

Participants estimated that 47% (range 14% - 80%) of women who are seen in gynaecological clinics were overweight and 30% (range 10% - 60%) were obese. Three superordinate themes emerged to describe the role of obesity in the help-seeking process and service provision in gynaecological cancer services: (a) *low disease knowledge or willingness to act* (i.e. low awareness of obesity as risk factor for disease, acceptance of obese body size), (b) *practice adapted to accommodate for obesity* (i.e. special accommodations/equipment needed, treatment risks, complications and examination difficulties, challenges of advising for weight loss), (c) *the unpleasant patient experience* (i.e. embarrassment with body exposure and special adaptations made during examination, obesity-related judgmental attitudes from professionals).

Theme 1.1. Low disease knowledge or willingness to act. All respondents were in agreement that the obese patients who attended their service were at an increased risk of developing chronic diseases and some gynaecological cancers (i.e. endometrial/womb & ovarian). Participants reported that they experienced patients to have a poor awareness of the association between obesity and the development of gynaecological cancers. Some professionals further stated that participants might be aware of their risk for developing other chronic diseases, such as diabetes and heart disease, but not necessarily gynaecological cancers.

> *HCP11: People are aware of obesity and heart disease risks. I think people are less aware of the link between obesity and chronic obstructive airways disease and cancer. (Male, Gynae-oncology Consultant)*

> *HCP14: They interviewed one of my patients and she basically said, "I had no idea [obesity] caused this cancer." Womb cancer from obesity...is actually not as known as you think it should be. Not in the lay public anyway. (Female, Gynae-oncology Consultant)*

Participants also highlighted the clinical challenges they have experienced when educating patients about the indirect relationship between the symptoms they are experiencing and their increased risk of developing a disease.

> *HCP10: The challenge is encouraging women to relate their symptoms and their weight. There's a big disconnect... They do not understand how weight can be responsible for troubles. (Male, Gynaecology Consultant)*

Despite patients having some knowledge of their risks for developing disease, participants reported that they might choose not to change their behaviour and accept their larger size as unalterable. Participants described a perceived acceptance amongst obese patients of their larger body size as a product of life-long obesity, past failed attempts at weight-loss, and older age. This acceptance of a larger size was described as a potential barrier to help-seeking in the context of aging and potential gynaecological cancer symptoms.

> *HCP12: But to be honest, the patients that come in that do carry the extra weight, they tend to know that their weight is an issue, but they don't seem to act on it. They seem*

> *to think, "Oh well at my age it doesn't really matter." (Female, Gynaecological Nurse Specialist)*

Theme 1.2. Practice adapted to accommodate obesity. Participants described specialised adaptations and equipment necessary to appropriately care for obese female patients in the gynaecological services, which included: hoists for mobilisation, longer speculums for examination, and larger MRI/CT scanners, measuring scales, wheelchairs, gowns, chairs, tables and beds. Respondents reported the potential for delayed treatment when appropriate equipment was unavailable.

> *HCP4: I had a lovely lady the other day and I had to measure her girth because she had a very big BMI. I had to sellotape two tapes together, which was horrible because we hadn't got a tape measure long enough and she then had to wait to use the extra wide scanner, which delayed her treatment. If they're less mobile a hoist for lifting [is necessary], which is very difficult for everybody, and in [the] extended recovery unit we've had to buy a whole load of bariatric equipment; so extra big commodes for heavy women, extra big beds, big wheel chairs and stuff like that. (Female, Specialist Gynae-oncology Nurse)*

When asked about what it was like to treat obese women in their service, participants reported clinical challenges, surgical risks and treatment delays caused by obesity (e.g. anaesthetic risks, examination difficulties, radiotherapy, scanning complications, financial burden and surgery risks). Participants acknowledged risks and potential implications of obesity on patient care, in which obesity and comorbid diseases may reduce treatment effectiveness, positive outcomes, and further complicate the recovery process.

> *HCP12: It tends to be more difficult to locate the cervix. And it's harder to do hysteroscopies on larger weight than it is on normal weight ladies. (Female, Gynaecological Nurse Specialist)*

> *HCP9: Challenging. We are dealing with obese patients and on top of that they may have other inter-current illnesses from underactive thyroid, heart disease, to orthopaedic problems from the stress they put on their back ... [and] blood pressure. Secondly, access to the organs that we need to get to, take out. Thirdly, recovery with wound infections, because fat does not have the same blood supply as muscle. Intensive recovery services, because you're probably not aware that obese women under-breathe. (Male, Gynae-oncology Consultant)*

To reduce the risks and challenges associated with diagnosing and treating obese patients in gynaecological care, professionals may advise patients to lose weight. Participants acknowledged the clinical importance and challenges associated with this. Participants agreed that occasionally weight-loss might be necessary prior to commencing treatment. The excerpt below describes how a woman's inability to lose weight delayed her treatment.

> *HCP2: And she knew and I knew, and I said to her, "We would normally do this and here we are watching you sitting on a potential cancer coming out and I can't do it because you are just too risky to put asleep."*
>
> *RESEARCHER: Right, and what happened in her case?*
>
> *HCP2: To the best of my knowledge she's still being monitored [for cancer growth, because treatment is too risky]. (Male, Gynae-oncology Consultant)*

Nevertheless, participants described how they might prioritize patient weight-loss but only according to complex parameters.

> *HCP19: If I'm referring someone for suspected endometrial cancer it's about the bottom of my priority list to be advising about her weight, because quite frankly she's got more important things to worry about. She can't lose weight in two weeks that's going to make any difference. However, following somebody up in a less acute situation then you just say, "You know you're a bit on the overweight don't you?" (Female, GP)*

Participants reported challenges with discussing obesity related risks and delivering weight-loss advice in a supportive and sensitive manner that maintains a positive and effective doctor-patient relationship. Participant narrative about weight-loss discussions prioritised effective doctor-patient communication for practical rather than patient-centred reasons. As such, respondents described unsuccessful communication attempts as having the ability to cause patient upset, which may increase the likelihood of delayed in patient help-seeking for current and future gynaecological symptoms. Some HCPs reported their own embarrassment in initiating the weight-loss conversation with patients, often choosing not to discuss weight management as a way of avoiding the possibility of offending a patient. When the researcher asked if a participant had ever advised a patient to lose weight, a gynaecological oncology nurse explained how she avoided discussions about weight by offering suggestions that could lead to weight-loss without mentioning weight itself.

> *HCP6: To be honest with you, no I haven't, because I feel that that's one thing I'm still very sensitive [about this], especially to women. So I've never really told them directly about, "Yes you need to lose weight." No I haven't. It's really bad, because I should as a healthcare professional, but it's difficult to say things that will not offend them. So, I say it very indirectly like, exercise, healthy lifestyle, healthy this. (Female, Gynae-oncology Staff Nurse)*

Additionally, the clinical time limitations in GP practice may also limit the opportunities for professionals to discuss weight-loss plans with patients. For example:

> *HCP20: It is one of those things that sometimes you don't want to raise with a patient, because you're very short of time and you know that if you sort of say, "Oh and by the way you need to lose weight", you're opening this other of can of worms that, you know, you ought to deal with that same day, but when you're running short of time it's difficult to. So sometimes you might not raise it even if you know that it needs to be addressed. (Female, GP)*

Although clinicians can be an important resource for patients trying to make healthier lifestyle choices, it was acknowledged that advising patients to lose weight could be challenging. Participants reported that successful weight management occurred when HCPs were able to provide patients with information and resources, including clearly structured individual weight-loss plans.

> *HCP14: Unless you have a clear plan for it it's unhelpful. I do say, "I think because you're bigger this has contributed to your cancer." But I think it's unhelpful to say, "lose weight", and not give people a clear structure for how to lose weight, because it's very naïve to think that these people have got SO little understanding of themselves that they cannot see that they are fat. (Female, Gynae-oncology Consultant)*

Respondents reported that some doctors might focus excessively on a patient's weight issue and neglect to attend to a patient's primary concern for the visit, which may be perceived by the patient as blaming or "beating them up" in an attempt to manage weight.

> *HCP10: The moment you start talking about weight you are beating them up. They know all about weight, "No this is a heavy period. It's got nothing to do with weight."*

> *So you try to create awareness and acceptance and it creates a strained relationship. It's not easy…They know they are overweight but that's not why they came. You can see how frustrated they are. (Male Gynaecology Consultant)*

Furthermore, respondents highlighted the importance of engaging in supportive conversations with patients and described that non-supportive language regarding weight-loss was seen to suggest "patient blame" and was often interpreted by the patient as insensitive or derogatory (e.g. blaming the patient for not losing weight after agreeing to lose weight at their previous visit; labelling obesity as the cause for all or most medical problems; labelling patient as big, fat or obese). Participants believed that patients who had previous negative experiences in communications with their doctors initiating weight-loss discussions were less likely to attend regular health screening appointments.

> *HCP3: Doctors can actually be quite derogatory and nursing staff, especially in GP practices, [be-]cause you go to be screened and all of a sudden you've been put in for diabetic checks because you are large, and then you're given grief about, 'you need to go on a diet because you are so big'[...]. People then don't attend follow up for their smear result because if they go back then their gonna have the, "I hope you've changed your diet? Have you done this? Have you thought about this?" (Male, Radiographer)*

Theme 1.3. The unpleasant patient experience. An experiential interview question required participants to place themselves in the shoes of their obese female patients. When asked how they would experience their service if they were an obese female, participants identified common barriers associated with their own services (e.g. waiting room seats with arm rests that do not fit larger body sizes, limited access to larger sized wheelchairs, and examination tables that are too narrow or too high and difficult to get up onto for those with mobility issues due to obesity), along with the recognition of discomfort experienced when the subject of weight arises in clinic, the potential for patient embarrassment when undressing for examination, and discomfort during examination.

> *HCP9: I suspect that first of all, I might feel embarrassed about displaying my body to anybody and that might prevent me to go and see somebody. Secondly, when I do go and see somebody I might have difficulty fitting into the chair that they have in the waiting room, in the consulting room, particularly if those chairs have side arms. Because, you know, my bottom might to be too large for those. [...] Maybe problems with access if there were no lifts or escalators, because I might have difficulty climbing the stairs. I would have a problem with doctors looking for my cervix, they would spend a lot of time fiddling around and would cause me more discomfort or even pain doing so. (Male, Gynae-oncology Consultant)*

HCPs' perceived barriers and motivators for help-seeking amongst obese women with symptoms of gynaecological cancers

Four super-ordinate themes emerged to describe HCPs' beliefs about the barriers to help-seeking experienced by obese women. These included: (a) *poor understanding of the risks and symptoms of gynaecological cancers*, (b) *obesity as a physical barrier* (i.e. mobility, symptom recognition/interpretation difficulties), (c) *low body-esteem* (i.e. embarrassment) and *perceived HCPs' negative attitudes about obesity* (experienced by patients at previous clinic visits), and (d) *sociocultural and economic barriers* (i.e. language, religious and cultural values).

Four participants stated that from their own professional experience obesity was not a barrier to help-seeking, although participants identified ways in which obesity *might* be a potential barrier for obese women to seek help for symptoms of gynaecological cancers.

These participants stated that body size does not pose a barrier in the recognition of symptoms of gynaecological cancer.

HCP14: I don't think that the fact that they've got an altered body, because they are eating quite a lot should mean that then they are not in touch with what's going on. I don't feel that anyway. (Female, Gynae-oncology Consultant)

Theme 2.1. Poor understanding of the risks and symptoms of gynaecological cancers. Some participants identified a difference between experiencing distinct symptoms (e.g. post-menopausal bleeding) and more vague symptoms (e.g. abdominal pain, bloating) of gynaecological cancers, explaining that obesity would not play a role in experiencing distinct symptoms of post-menopausal bleeding, as most women are aware of its abnormality and risks posed by this symptom.

HCP2: For cases of abnormal bleeding, particularly in the womb cancer women tend to take action. (Male, Gynae-oncology Consultant)

HCPs agreed that patients might experience difficulties when identifying and interpreting the often-vague symptoms of gynaecological cancers, and further understanding the risk that obesity has on the development of the disease. The presence of other diseases, illnesses and comorbidities associated with obesity (e.g. cardiovascular disease, hypertension, type 2 diabetes, polycystic ovary syndrome) may create a challenge in interpreting symptoms, given that obesity-related symptoms may mimic those of gynaecological cancers (e.g. abdominal bloating, irregular bleeding, stomach pains).

HCP16: With ovarian cancer, abdominal symptoms of an abdominal mass may be more difficult to detect than in a slim or normal build woman... Symptoms like irritable bowel, where they get pains sort of [like gynaecological symptoms]... Obesity

> *can sometimes mask the symptoms, [which may lead to a] disadvantage in recognition or awareness of symptoms. (Female, Gynae-oncology Nurse Specialist)*

According to some HCPs, the vague and non-specific symptoms of many gynaecological cancers may lead to misinterpreting symptoms as benign by patients as well as HCPs. This can delay help-seeking and further delay treatment.

> *HCP7: Ovarian cancer is quite delayed by the time they go to the GP because they don't realise kind of that they have any problem. You know, they put it down to the normal kind of symptoms like abdominal bloating or distension, so that kind of stuff. (Male, Gynae-oncology Registrar)*

Patients are motivated to seek help by the salience of symptoms or when the experience of their symptoms worsen, become too painful or unmanageable.

> *HCP10: They have symptoms or problems that you just cannot ignore, so with your abdominal distension you cannot eat [...], your bowels, waterworks aren't working properly or you're bleeding down below in a haemorrhagic kind of way. You know, your pads [are] all over the place... Take a vulva cancer, it can sit there, go along for a period, then it becomes painful and your Panadol doesn't get rid of the pain, and you need to go up on the pain killers. You are in a position where you have to see a doctor or stay in pain. (Male, Gynaecology Consultant)*

Theme 2.2. Obesity as physical barrier. Despite the four HCPs who initially did not acknowledge obesity as a help-seeking barrier, the majority of HCPs perceived obesity to be a potential barrier, reporting that the physical barrier of obesity is an important factor that affects one's mobility and ability to undertake self-examination behaviours. Barriers for those with mobility problems included experiencing physical difficulty in getting up onto the examination table during clinic visits, which was perceived to be physically straining to the patient. HCPs further discussed potential embarrassment due to assumed difficulties encountered by a consultant during examinations, which could be complicated by a patient's larger size.

> *HCP16: But I have had conversations with obese ladies that presented late and we often say, you know, "When did you have the symptoms and you know, if you had these symptoms you could have come earlier". [...] They're just embarrassed, because they think we'd have difficulty examining them. Or getting [them] on and off the table… (Female, Gynae-oncology Nurse Specialist)*

In addition, participants recognised the potential physical challenges of self-examination and interpreting abdominal or pelvic organ swelling as a potential symptom of gynaecological cancers for many obese women.

> *HCP2: For vulva cancer there could be an irritation, and [they're] not being able to visualise it. The slimmer you are, obviously the easier. You could see situations like in ovarian, dealing with symptoms that we associate with [cancer, such as] abdominal distension, so you could have quite a big cyst in there and I suppose if you're obese, potentially not recognise this compared to somebody who is slim. (Male, Gynae-oncology Consultant)*

These clinical challenges may additionally impact on future help-seeking behaviour as a consequence of previous negative experiences in clinic. Previous negative experiences in clinic were described as any negative experience that a patient has experienced in clinic, and includes negative psychological and physical impact whilst in contact with a HCP (as discussed above).

Theme 2.3. Low body-esteem/ embarrassment and perceived HCP negative attitudes about obesity. HCPs perceived that low body-esteem (i.e. negative self-evaluation of one's body) amongst obese women could act as a potential barrier to help-seeking. Body-esteem was used as a term to describe the perceived embarrassment and discomfort women often experience when revealing their bodies during vaginal and pelvic examination and an embarrassment of one's size or weight in the context of perceived/assumed negative judgement from HCPs by patients during clinic visits.

HCP16: They say that they're embarrassed with their perception of how we may treat them or may look at them... (Female, Gynae-oncology Nurse Specialist)

Respondents described their assumption that some GPs may falsely interpret presenting symptoms as a comorbid condition and therefore a consequence of their patients' obesity. This initial judgment may encourage patients to withhold information about new symptoms that may be unrelated to any comorbidity, but represent a distinct symptom of gynaecological cancers.

HCP18: I think there is a perception from overweight women that they're going to be judged because of their weight. I think there are issues around how some GPs… talk to patients and label them. Ultimately I think that a lot of overweight women feel that anything that they go to their GP about will be labelled as a weight-related problem. (Female, Gynae-oncology Specialist Nurse)

Some participants believed that patients avoided seeking health advice from a HCP due to previous negative experiences where weight-loss was the primary issue under discussion. Specifically, one participant discussed a patient's apprehension about attending a doctor's appointment, knowing she would be told once again to lose weight. In such cases a patient may feel a sense of embarrassment about their own body size and their lack of weight-loss since their last visit.

> *HCP15: When they go and see their GP each time they get lectured about dieting, because of the diabetes and things like that, so they may not mention any bleeding or issues like that... If they go in with another problem which could be linked with their obesity they are trying to avoid another lecture about their weight problems. (Female, Gynae-oncology Specialist Nurse Practitioner)*

The doctor-patient relationship was viewed as a key mediator of prompt help-seeking for symptoms. Female patients could be motivated by their GP to participate in regular screenings, and for those who regularly visit their GP for comorbidity management these visits could be an opportunity to learn about the importance of early detection and help-seeking for abnormal symptoms.

> *HCP10: The GPs always give out information encouraging bleeding women to report in menopause. (Male)*

Theme 2.4. Sociocultural and economic barriers. It is not always possible to separate obesity from the general factors that might act as barriers for all women regardless of size. This highlights the importance of also acknowledging sociocultural and economic barriers (i.e. language, cultural customs, religion) that could impact on an obese woman’s decision and ability to seek help for symptoms of gynaecological cancers. Such barriers included a link between obesity and socio-economic deprivation, which respondents described as influencing an individual’s views of their self-worth and esteem.

> *HCP14: Socio-economic status is intimately associated with obesity. It's difficult to distinguish [what] the cause of the mind-set [of the patient is], "No-one will listen to*

> *me anyway" Um, you know, "The world's against me." (Female, Gynae-oncology Consultant)*

The perceived difficulties with language for non-English speaking patients included interpretation, mistranslations or withholding of diagnostic information. Respondents observed that often families restricted communication of negative information or diagnosis to protect the patient.

> *HCP11: Younger generations come in as interpreter and want to protect the patient from negative diagnostic information. They don't want to tell mum that she's got a cancer. (Male, Gynae-oncology Consultant)*

Participants identified Muslim women and women of South Asian origin as often experiencing limited access to health information, and practicing cultural and religious customs that may impact help-seeking, such as a patient's preference to be examined by a female doctor, potentially involving a longer waiting period.

> *HCP13: Many women from Pakistani and Bengali background refuse a male doctor and request a female for gynaecology. Some of them leave the clinic despite the fact that we are telling them they may be having cancer. (Male, Gynaecology Consultant)*

Cultural barriers were perceived not only amongst the migrant or ethnic minority groups, but also amongst indigenous white British patients, reporting that often elderly white British women did not wish to bother their doctor with general health problems and that they interpreted their symptoms to be related to aging. This was referred to as the "stiff upper lip" phenomenon.

> *HCP2: Reluctance of people to seek advice from their doctor due to the 'English stiff upper lip' thing, 'don't bother the doctor' and that was one of the barriers. (Male, Gynae-oncology Consultant)*

Participants discussed the significant impact that a patient's community and social network has on the help-seeking process by stating that often patients approach family or friends with questions regarding symptoms prior to consulting a HCP. Respondents perceived that a patient's help-seeking practices were often motivated by family or friends who had received a gynaecological cancer diagnosis in the past, or by direct encouragement from family or friends.

> *HCP15: Maybe because of the BRACA [breast cancer gene mutation], history of breast cancer as well... or friends her age who have recently had cancers. So she was quite anxious because of the situation with other friends, which made her access the GP quite quickly because she didn't want to go down that route. (Female, Gynaecological Oncology Specialist Nurse)*

Suggested Interventions

Participants provided some insightful suggestions for future interventions that were informed by their own experience. Community education was suggested to engage the public in gaining knowledge of the symptoms of gynaecological cancers (e.g. through media and information distribution in public stores, community weight-loss programme and primary care settings). Furthermore, participants expressed that education should also target HCPs by focusing on improving doctor-patient communication when addressing the associated risks of obesity and the possible emotional and sociocultural barriers that may affect help-seeking for gynaecological cancers.

It was suggested that gynaecological awareness should be addressed by an intervention to provide the public with information regarding symptoms and risk factors for gynaecological cancers, and highlighting the importance of early presentation to healthcare. Participants suggested that leaflets should be available during regular comorbid disease appointments in GP practices and other healthcare services including specialist weight-loss programmes.

HCP15: If you're targeting them who come in with the comorbidities, educating them about the symptoms so they would attend earlier with the symptoms. So, "you have lost lots of unopposed oestrogen, you are at risk of endometrial cancer if you do have any bleeding go to your GP straight away. So that you can catch cancers at an earlier stage rather than later." (Female, Gynaecological Oncology Advanced Specialist Nurse)

HCP9: We can go to weight watchers and all of the weight reducing organisations to solicit their help in distributing literature about cancers. (Male, Gynaecological Oncology Consultant)

All participants agreed that interventions should be run within communities as well, as well as in the primary care settings. Information should therefore be made available in community weight-loss associations, supermarkets, fast food restaurants, public toilets, and leaflets may also be mailed to homes.

HCP11: The classic response to that is in GP surgeries, but if these are people that haven't accessed healthcare that's a pretty pointless thing to do. So where do people go? They go to supermarkets, restaurants, fast-food restaurants, toilets. But I would target supermarkets first, because if there's one building in a town now that people access on more regular basis than anywhere else it would be a food outlet. And I suppose that's where the problem starts isn't it. Leaflets at checkouts. (Male, Gynaecological Oncology Consultant)

Participants expressed the importance of educating patients about the increased risk for disease and morbidity that is associated with obesity, and the necessity of doing so in a serious and supportive manner. This can motivate women to seek help for symptoms.

> *HCP2: You can be nice to them or you can frighten the life out of them. The perception is abnormal [cervical] smear means cancer. We know that's not true, but nobody ever shouts about that. So it's a little frightener. One way that you can do things is be blunt and put up. But to say, you're doing too much of this you're doing too much of this [sigh]. Yeah, you get tired of it, you get fed up, and-but you do get an impact when you tie in obesity with cancer-with symptoms of cancer. So obesity is associated with cancer, "your risks are increased by this if you have symptoms you're one of the people we should be targeting to get to the doctor". (Male, Gynaecological Oncology Consultant)*

Interventions were suggested to encourage obese women to seek help for gynaecological symptoms including community run interventions to improve awareness of the risk factors and symptoms involved in gynaecological cancers (e.g. through media and information distribution in public stores, community weight-loss programme and primary care settings). A service run intervention was suggested by participants to train HCPs about the importance of supportive doctor-patient communications during the clinical encounter with obese women. Furthermore, sociocultural factors should be taken into account in the development and application of interventions.

Discussion and Conclusion

The aims of this study were to explore HCPs' perspectives on (a) the use of gynaecological services amongst obese patients presenting with symptoms of gynaecological cancers, (b) to explore their beliefs about the potential barriers and motivators that influence help-seeking amongst obese women presenting with symptoms of gynaecological cancers, and (c) to provide suggestions for possible interventions amongst this population (as a secondary aim). HCPs working in gynaecological cancer services described a range of factors that present as difficulties and challenges for obese women in their practice, the reasons they believe these women to be at increased risk of developing cancer, and the general and specific factors that may influence patients' decisions to seek help for symptoms.

HCPs hold specific beliefs about the obese women who seek help from their services, and described these patients as a challenging group to work within the context of gynaecological cancer services. The impact of reading these quotes from the patients' perspective should be recognised as some may find the quotes judgmental or highly sensitive, however it is apparent in the narratives that the HCPs have to prioritise the patient's needs for best care, and that these barriers are discussed with the aim of highlighting possible changes to practice in an often practical rather than patient-centred way, with the exception of the nurse narratives which appear to be more patient-centred in describing the experience of patients in their clinics. Additionally, it should be acknowledged that the research topic itself, and the questions asked, which addressed the barriers to help-seeking and challenges in working with this population, may have impacted participant responses given the nature of the open-ended interview schedule that required participants to explore how obesity *could possibly* pose as a challenge rather than asking them closed ended questions with yes or no as available responses.

The clinical challenges of obesity (e.g. anaesthetic risks, examination difficulties, radiotherapy, limited access to suitable equipment, scanning complications and surgery risks) were reported to be important factors in impacting the quality of patient care, diagnosis and treatment (Ferrante et al., 2009; Whittemore et al., 2005). Given the increasing incidence of obesity and endometrial cancer (World Cancer Research Fund/American Institute for Cancer Research, 2013; Reeves et al., 2007), it is necessary for services to provide obese women with the best quality care by ensuring that clinical equipment is available to accommodate larger body sizes (Whittemore et al., 2005).

Further clinical challenges arise when patients lack the awareness of risks associated with their weight, particularly those that increase the risk for chronic disease (Soliman et al., 2008), and when patients feel a body dissatisfaction that leads to the experience of embarrassment during their clinic visits (Amy et al., 2005; Ridolfi & Crowther, 2013). Nevertheless, some women were perceived to have accepted their obese size, which may make it more difficult for women to understand their risks and reduce their weight (where they believe obesity is not a concern), however evidence does not exist in the literature to suggest that fat acceptance correlates with a low body awareness or low disease-risk awareness. Furthermore, respondents reported challenges in discussing weight and weight-loss with their patients. To cope with these challenges, participants described the ways in which they adapt their practice to serve the needs of this growing population.

A key finding suggests that HCPs believe that discussing obesity-related risks and advising patients to lose weight can be an essential clinical role for HCPs in the UK and worldwide (Rose et al., 2013; Jackson et al., 2013). However, despite public health initiatives in the UK and clinical guidelines that require HCPs to discuss weight-related issues and assist with in weight management programmes (De Normanville, Payne, & Ion, 2011; National Institute for Clinical Excellence [NICE] guidelines, 2014; Royal College of General Practitioners, 2014), HCPs continue to find weight-related discussions with their patients to be a difficult and uncomfortable experience (Jackson et al., 2013). Participants justified not doing so according to specific conditions (e.g. prioritising treatment over discussion of weight, not wanting to “insult” the patient). For example, participants perceived that some patients might experience such discussions as blaming or shaming, particularly when patients had failed to lose weight since their last appointment (Alegria Drury & Louis, 2002). Such discussions were also described as having the potential to increase feelings of embarrassment, particularly while undressing for examination, and when anticipating clinical difficulty during examination due to an individual’s larger size (Smith, Pope, & Botha, 2005). Despite the clinical difficulties, respondents reported that patients who have positive or supportive relationships with their doctors are more likely to feel comfortable to seek help for symptoms, adhere to treatment, and have better health outcomes than patients who have a negative or absent relationship with a HCP (Auer, Sarol, Tanner & Mitchel, 2000; Phelan et al., 2015; Befort et al., 2006; Bogart, Bird, Walt, Delahanty & Figler, 2004). This highlights the importance of positive and supportive communication in doctor-patient encounters.

Participants were concerned about harming the doctor-patient relationship through discussions of weight, given that negative doctor-patient relationships can discourage future patient healthcare utilisation (Ferrante et al., 2009; Puhl & Heuer, 2009; Bocquier et al. 2005). Therefore, clinicians may benefit from training that provides helpful ways to empathetically address weight-loss concerns with their patients in clinic, such as engaging in supportive conversation with patients regarding weight-loss, and providing structured individual weight-loss plans with follow-up visits (Jackson et al., 2013). Although weight-loss plans are most suited to primary care services, all HCPs in both primary and secondary care services should be trained to discuss weight concerns in a respectful manner that encourages healthy lifestyle changes amongst women, despite previous unsuccessful weight-loss efforts (NICE, 2014).

The results of this study identified that HCPs believe obese women face a number of psychological, cultural, economic and at times physical barriers in their journey toward medical help-seeking for gynaecological cancers symptoms. Key findings suggested that HCPs believe obese women to have a poor understanding of the symptoms and risks of gynaecological cancers, which is described as a key factor that may lead to the delay in help-seeking (Boxell et al., 2012; Sheikh & Ogden, 1998; Jayde, White & Blomfield, 2010; Soliman et al., 2008) for this group. This lack of awareness is further perpetuated by the vague and non-specific symptoms of gynaecological cancers, which may lead to misinterpretation of symptoms as benign by patients *and* HCPs who may relate symptoms to weight-related issues (e.g. bloating, changes in bowel habits, back pain), thereby acting as a barrier to individuals requiring help for malignant symptoms of gynaecological cancers (Macleod et al., 2009; Smith, Pope, & Botha, 2005).

The literature suggests that body image disturbance and embarrassment to expose one's body during clinical examination is a common barrier to the utilisation of medical services for obese patients (Alegria, Drury, & Louis, 2002; Amy et al., 2005; Ridolfi & Crowther, 2013; Smith, Pope, & Botha, 2005). Findings were similar to literature reporting that non-attendance in *preventative health screening* programmes amongst obese women was due to barriers of weight-stigma and dismissive or derogatory language received from HCPs during clinic visits (Phelan, et al., 2015; Puhl & Brownell, 2006; Puhl & Heuer, 2009) and concerns about limitations with equipment relating to weight and or size restrictions for equipment (Uppot, 2007).

Participants described various ways in which the context around women could influence help-seeking. HCPs associated economic deprivation with obesity and lower awareness of disease risks with delayed help-seeking. These general, contextual and cultural factors are important to consider when investigating the experience of seeking help for gynaecological symptoms given that they have been shown to impact attendance at regular cervical screenings amongst minority ethnic groups (Marlow, Waller, & Wardle, 2015). Nevertheless, it is difficult to separate one's context and social world from obesity, given the associations with obesity, sociodemographic and lifestyle factors (Gold et al., 2000). A study by Ogden et al. (2001) highlighted this relationship with obesity in a study which reported that patients believed their obesity was due to medical problems and economic deprivation. Nevertheless, further investigation is needed to identify linkages between economic deprivation and obesity (Evans, Newton, Rutas, MacDonald, Morris, 2000) in the context of medical help-seeking, which the results of this study highlight may also be associated with self-worth or esteem. Furthermore, an individual's social milieu and disclosure to one's social network has been shown to impact help-seeking by influencing a patient's perception of symptom severity, whereby lay persons may provide information regarding a symptom that can encourage prompt help-seeking (Burgess et al., 2008; Calnan, 1983; Ramirez, Westcombe, Burgess, Sutton, Littlejohns, & Richards, 1999). An individual's cultural context may further act as a barrier to help-seeking, where non-English speaking patients or those with low literacy skills have limited access to cancer awareness information (i.e. brochures written in English, posters, advertisements) and where effective doctor-patient communication may be limited (Szczepura, 2005). A review of the literature supports the findings of this study, suggesting that social and religious beliefs may impact delay in help-seeking for symptoms (e.g. Muslim females waiting to see a female doctor; Chaliha & Stanton, 1999; Szczepura, 2005), different cultural health beliefs and practices (Bener et al., 2002), and the 'British stiff upper lip' (Forbes et al., 2013). Results also suggested that healthcare provision should be sensitive to the needs of religious or cultural groups (Karliner, Jacobs, Hm Chen, Mutha, 2007; Szczepura, 2005). Therefore, social and cultural influences as well as physical accommodations should be considered in the development of an intervention to improve help-seeking.

HCPs offered insight into healthcare service barriers and factors impacting the help-seeking behaviours of obese patients. Participants provided information regarding the potential physical, psychological and social barriers to help-seeking, and discussed important clinical challenges that HCPs face in working with obese women in gynaecological services. Results initially suggest a need to improve awareness of gynaecological symptoms and risk factors amongst obese women, and the need for service improvement to sensitively accommodate obese patients in cancer care and GP services.

Limitations and Future Directions

Results of the study may have been limited by the lack of gender variability recruited for nurses, in which all eight participant nurses were female, and responses may have differed if the study obtained the male nurse perspective. Nevertheless, there were no obvious gender differences in the responses of the sample as a whole.

With the growing number of overweight and obese patients, practices must be able to accommodate larger sizes with the availability of appropriate equipment including larger sized MRI and CT scanners, wheelchairs, examination tables, beds, and hoists for mobilization. Clinicians may benefit from training on time-efficient and supportive communication skills to discuss weight-related risks and to prioritise the appropriateness of weight-loss along the treatment pathway. Training may further increase clinicians' self-efficacy to discuss and support weight-loss amongst this population and aid in maintaining a positive doctor-patient relationship while raising awareness of cancer risks amongst obese patients.

The results of this study build a foundation for patient-focused research and identifies a potential need for an intervention to increase public awareness about symptoms and risk factors for gynaecological cancers (in primary care and community settings), the need to provide supportive environments which handle the specific needs of this group in a sensitive manner and the need for intervention development to acknowledge the wider cultural factors that can further impact help-seeking for *all* women experiencing symptoms of gynaecological cancers (Low, Simon, Waller, Wardle, & Menon, 2013a; Low, Waller, Menon, Jones, Reid, & Simon, 2013b).

CHAPTER 5: PREDICTING HELP-SEEKING FOR SYMPTOMS OF POST-MENOPAUSAL BLEEDING

Introduction

Obesity has been associated with an increased risk of developing some gynaecological cancers, including endometrial and ovarian cancers. Endometrial cancer is the most common gynaecological cancer and it has the strongest obesity-related risk of 81% for every 5 kg/m^2 increase in Body Mass Index (BMI; Stevens, Jacobs, Patel, Sun, Gapstur, & McCullough, 2014). In addition, women report that barriers related to their weight contribute to a delay in the utilisation of healthcare services, encompassing gynaecological and breast cancer preventative screening programmes (Amy, Aalbord, Lyons, & Keranen, 2005; Aldrich & Hackley, 2010; Aphramor, 2012). However, it is unknown whether a similar relationship exists when women are actively experiencing symptoms indicative of gynaecological cancers, given that the specific factors that contribute to obese women extending the time to presentation at healthcare services for symptoms of gynaecological cancer have not been identified by previous research.

Obesity and related comorbidities, including diabetes and hyperplasia (Hardiman, Plillay, & Atiomo, 2003), have been associated with post-menopausal bleeding (PMB) and the development of endometrial cancer (See Chapter 2; Bray, dos Santos Silvia, Moller, & Weiderpass, 2005; Breijer et al., 2010; Memon, 2009). Endometrial cancer is a hormonal *carcinogenesis*, which means that the storage of oestrogen in body fat can cause a thickening of the womb lining (i.e. the endometrium) that leads to PMB in obese women (Memon, 2009; Tinelli, Vergara, Martignago, Leo, Malvasi, & Tinelli, 2008). This key risk factor is associated with increased morbidity in endometrial cancer (Calle & Kaaks, 2004), despite it being typically characterised by a high survival rate when compared to other gynaecological cancers (Cancer Research UK, 2014b). Furthermore, the reviewed literature suggests that disease awareness impacts on time to help-seeking (Jones & Johnson, 2012), and that there may be a low awareness of the risks, particularly those associated with obesity and the development of gynaecological cancers amongst the general public (Soliman et al., 2008). Therefore, obese women are at an increased risk of developing gynaecological cancers and of receiving later-stage diagnosis and treatment.

Post-Menopausal Bleeding (PMB)

PMB is defined as an episode of bleeding twelve months or more after a woman's last menstrual period (Scottish Intercollegiate Guidelines Network, 2002). PMB can be due to endometrial hyperplasia and associated cell tumours of the ovary (Koukourakis et al., 2008) or a symptom of cervical or vagina cancers, although of the cancers it is more commonly a symptom of endometrial cancer (Newell & Overton, 2012; Piura, Yanai-Inbar, Rabinovich, Zalmanov, & Goldstein, 1999). An estimated 95% of women diagnosed with endometrial cancer present at healthcare services with the symptom of PMB (Brenner, 1996; Parkin, Bray, Ferlay, & Pisani, 2001). Due to the strong link between obesity and the development of endometrial cancer, it is important to study associated symptom(s) and to assess public knowledge of gynaecological cancers and obesity-related risk.

Help-seeking for PMB is a complex and dynamic process. Despite the distinct nature of the symptom it should not be assumed that individuals would seek help for symptoms of PMB. Although PMB is commonly recognised by patients as an abnormal experience or a warning sign for cancer by many menopausal and post-menopausal women given that intermittent bleeding is a common, yet often concerning symptom of the menopause (Brunswick, Wardle, & Jarvis, 2001; De Nooijer, Lechner, & De Vries, 2002a; Trivers, Rodriguez, Hawkins, Cooper, Polonec, Gelb, & Purvis Cooper, 2008), it often lacks the salience needed to appraise the symptom as severe enough to seek medical attention, given that the bleeding does not usually cause pain and may not interfere greatly with daily functioning (Quaife et al., 2014). Consequently, women experiencing PMB may not seek help unless they have an awareness of the symptom as a warning sign of cancer (Robb et al., 2009).

Not recognising a symptom as suspicious is one of the most common reasons given by cancer patients for delayed help-seeking (Chapple, Ziebland, & McPherson, 2004; Smith, Pope, & Botha, 2005). A review by Jones and Johnson (2012) highlights the importance of this awareness and the surprising lack of knowledge amongst women regarding the risks of PMB. For example, findings of the Johnson and colleagues' (2011) study reported that half of the women who experienced abnormal bleeding were not aware that it was a warning sign for possible cancer and half waited more than one month before seeking medical help. Overall findings of the literature suggest a lack of awareness of symptoms of gynaecological cancers (Boxell et al., 2012; Jayde et al., 2010; Low, Waller, Monon, Jones, Reid, & Simon, 2013a), particularly amongst individuals of minority ethnic groups (Lindau, Tomori, Lyons, Langseth, Bennett, & Garcia, 2002; Soliman et al., 2008).

Aims and Hypotheses

The present study aimed to: (a) identify predictors of help-seeking for PMB amongst women in the general population, to (b) examine whether extended time to help-seeking differs between obese and non-obese women, to (c) to examine whether awareness about gynaecological cancers (risk factors and symptoms) differs between obese and non-obese women, and (d) to examine whether awareness about gynaecological cancers and extended time to help-seeking differs across ethnic groups. The factors examined included sociocultural and demographic factors, body image satisfaction, objective body measures (i.e. BMI & waist-to-hip ratio; World Health Organization [WHO], 2000; WHO, 2008a), mood, illness perceptions (i.e. timeline, consequences, control, illness coherence, emotional representations) (Leventhal, Brissette & Leventhal, 2003), previous health behaviours, social capital and gynaecological cancer awareness. It was hypothesised that a negative body image, an obese BMI, low awareness of the risk factors and/or symptoms of gynaecological cancers would predict an extended time to help-seeking. It was further hypothesised that previous, positive health behaviours would predict timely, more immediate help-seeking, and that aspects of social capital and illness perceptions, namely social support, illness control and coherence would predict time to help-seeking. Lastly, it was hypothesised that differences exist between obese and non-obese women regarding extended time to help-seeking, and that differences exist in awareness of gynaecological cancers amongst groups of obese and non-obese women, as well as White-European and South Asian, Asian and Black African/other ethnic groups.

Method

Design

The study employed a questionnaire design to explore whether there is a relationship between sociocultural and demographic factors, body image satisfaction, objective body size, mood, illness perceptions, previous health behaviours, social capital and gynaecological cancer awareness to identify potential differences across groups of ethnicity and obesity, and to further identify whether factors of obesity and ethnicity are associated with extended time to help-seeking for symptoms of PMB. See Appendix G for the Study Design Flow Chart.

The research project was sponsored by the University of Birmingham under the Research Governance Framework (Reference number: RG_13-315), and was approved by the

Black Country Committee of the National Research Ethics Service (14/WM/0117), and the Directorate of Research and Development of the Sandwell and West Birmingham Hospitals NHS Trust (Reference number: 13CAN71) to conduct the study at the City Hospital in Dudley and the Sandwell Hospital in Sandwell, Birmingham, West Midlands. See Appendix A.

The study consisted of a non-stratified sample of 164 women with variable BMIs who were approached when attending their first appointment at a West Midlands PMB clinic after receiving an urgent referral for a suspicious symptom of cancer (i.e. post-menopausal bleeding or abnormal vaginal discharge).

Recruitment and Sampling

Patients were recruited from Sandwell and West Birmingham Hospitals NHS Trust. Potential participants were approached during their first visit to the PMB clinic and asked if they wished to participate in the study by the researcher and/or staff nurses in the waiting room, while they waited to be seen by the clinician (all patients were verbally informed that their participation in the study would not delay their visit to see the clinician). Participants who expressed an interest in participating were provided with a questionnaire pack and given the option to complete the questionnaire in clinic, while the researcher was present to aid with completion, or to take it home to return to the researcher by post. The questionnaire pack included an information sheet (see Appendix H), a consent form (see Appendix I), a debrief form (see Appendix J) and the full questionnaire (see Appendix F) with a paper-tape measure and a pre-paid and addressed envelope for return if they wished to complete the questionnaire at home.

Measures

A number of factors (e.g. Sociocultural and demographic factors, body image satisfaction, illness perceptions, disease awareness) have been shown to delay help-seeking behaviour in women with gynaecological cancers. A comprehensive literature review was conducted (Chapters 1 & 2) to identify psychological scales and measures examining factors associated with increased time to help-seeking in this group of patients in order to best answer the study's research questions. The development of the questionnaire incorporated the theoretical framework of Leventhal's Self Regulation Model (SRM; Leventhal, Brissette, & Leventhal, 2003), the structure of the adapted Andersen's model of help-seeking (Andersen, Cacioppo, & Roberts, 1995) and factors and conceptual understandings of the help-seeking process from the Model of Pathways to Treatment (Scott et al., 2013; Walter et al., 2012), with a strict adherence to the study aims of exploring the journey to help-seeking and collecting quantitative information to test the hypotheses that specific factors influence help-seeking behaviour for PMB.

Methodology

Limitations present in delay and help-seeking literature informed the development of the questionnaire, accounting for concerns with the term delay (addressed in Chapter 2), and the retrospective study of help-seeking behaviour. Many help-seeking studies target individuals post-diagnosis, thus allowing for recall error and biased sampling (Finn et al, 2007). The present study therefore employed techniques to enhance recall in retrospective methods (Scott & Walter, 2010) through the use of a questionnaire, flow chart and open-ended recall of symptoms experienced employed during a pre-diagnosis stage. The study accounted for limitations inherent in help-seeking research through adherence to a theory-driven approach, a focus on symptom interpretation and dynamic patient processes in help-seeking (Andersen, et al., 2009; Scott & Walter, 2010). Furthermore, the study followed the Aarhus statements checklist for help-seeking research (see Appendix M).

Four staff nurses and healthcare assistants, who worked daily with the target population in PMB clinics in Birmingham, piloted the questionnaire. Staff gained feedback from clinic patients and colleagues regarding the appropriateness of the questions, wording and overall presentation of the questionnaire. As a result of this, wording was simplified and shortened to form more concise sentences that met the needs of the patients and enhanced comprehension, as well as increasing the likelihood of questionnaire completion during time-limited clinic appointments. Furthermore, the flow chart was simplified for ease of use by removing excess options that were deemed inappropriate for the population (e.g. period cycles).

Demographic information. Specific health beliefs often differ across cultures (Baumann, 2003; Adams & Salter, 2009). Therefore the demographics section was developed to comprehensively record important components of culture, ethnicity and socio-economic status. The demographic form included eleven questions to determine age, marital status, employment, personal deprivation, education, years of residence, country of origin, religion, ethnicity, and generations of English language speaking in the family (see Appendix F). To measure personal deprivation participants were asked to indicate their agreement with each statement (e.g. “I have no car available”; “I do not own a home”) by ticking the box next to each statement (Health Education Authority, 1995; McKay, 2010). Ticked statements were scored with a 1 and non-ticked statements were scored with a 0 (total score range 0 – 5), therefore higher scores indicated higher levels of deprivation (see Appendix E). Furthermore, to account for the multi-diverse population of Birmingham, the demographics section included items of cultural integration and acculturation (i.e., years of residence, language and generations of English language speaking), as informed by the literature highlighting the importance of migration factors in research with samples that are rich in cultural diversity (Bhopal, 2012; Phillimore, 2012).

Objective measures of obesity. Two measures of weight and body size included BMI and waist-to-hip ratio. Each participant's BMI was measured (height in metres and weight in kilograms) in clinic by a medically trained staff. BMI was calculated by the formula suggested by the WHO (2000), namely BMI = x KG / y M^2. Waist-to-hip ratio was calculated using a self-measure of hips and waist in centimetres (WHO, 2008a), and was measured using a tape-measure provided. The measure of waist-to-hip ratio was chosen as an additional objective measure of health (Bhopal et al., 1999; National Obesity Observatory, 2012), and is an ethnically reliable measure of weight-related health (Ashwell & Hsieh, 2005; Hsieh & Yoshinaga, 1995). According to the WHO (2008a), women with a waist-to-hip ratio of .8 or more are considered at risk of suffering from cardiovascular diseases and diabetes, and are categorised as obese and in an unhealthy body size. Obesity was defined according to WHO (2000) BMI weight categories (Underweight BMI < 18.5; Normal weight BMI 18.5 – 24.9; Overweight BMI 24 – 29.9; Obese BMI 30 – 39.9; Morbidly obese BMI > 39.9).

Body image. The Body Shape Questionnaire 16A (BSQ16A; Evans & Dolan, 1993; see Appendix F) measured body image satisfaction. The BSQ16A is a validated questionnaire employing 16 items on a six-point Likert scale questionnaire. The BSQ16A is suitable for the non-clinical assessment of body satisfaction, is identified as useful in studies of normal weight and obese samples. Permission to use this scale was granted from authors of the questionnaire (Cooper et al., 1987; Evans & Dolan, 1993) for use in the present research. Participants were asked to answer questions relating to how they have been feeling about their body over the past four weeks, and they were asked to indicate how often they thought about the their body shape with responses to items scaled from 1 (‘never’) to 6 (‘always’) (e.g. “Has eating even a small amount of food made you feel fat?”). Total scores ranged from 16 to 96. Outcome variables were defined by Evans and Dolan (1993) with total scores of 38 to 51 indicating ‘mild concern with shape’, 52 to 66 indicating ‘moderate concern with shape’ and scores over 66 indicating ‘marked concern with shape’. Reliability analyses showed good reliability (α = .94) for the scale (see Appendix K for reliability statistics of each scale).

Illness Perceptions. The Revised-Illness Perceptions Questionnaire (IPQ-R; Moss-Morris et al., 2002; see Appendix F) is a validated questionnaire used to measure illness representation subscales of timeline, timecycle, severity of perceived consequences, illness coherence, perceived personal control over one’s condition, perceived control that treatment has over the condition and emotional representations of illness. This scale has been used in gynaecological and cancer research (Gould, Brown, & Bramwell, 2009) with good internal consistency (α = 0.67 - 0.87) and retest reliability (0.46 – 0.87) (Moss-Morris et al., 2002). Free access for use of the IPQ-R and permission to adapt the questionnaire to suit specific illness populations was provided on the free access website (The Illness Perception

Questionnaire Website, 2015). IPQ-R consisted of thirty-eight statements on a five-point Likert scale from one ('strongly disagree') to five ('strongly agree') (e.g. perceived control: "What I do can determine whether my current problem gets better or worse"). An additional question asked participants to identify three possible causes of their symptom in an open-ended question (see Chapter 6 for perceived causes). Scoring was conducted in accordance with the IPQ-R scoring protocol (total possible scores ranged from 38 to 190; Moss-Morris et al., 2002; Weinman, Petrie, Sharpe, & Walker, 2000). Wording of the items were altered slightly to suit the target population for the study, replacing the word 'illness' with 'condition' or 'symptoms'. The Identity scale was removed, given that the current study was exploring one primary symptom (PMB). The reliability statistics for each subscale ranged from reduced to good reliability for timeline (6 items: $\alpha = 0.74$), cyclical timeline (4 items: $\alpha = 0.59$), consequences (6 items: $\alpha = 0.69$), illness coherence (5 items: $\alpha = 0.81$), personal control (6 items: $\alpha = 0.47$), treatment control (5 items: $\alpha = .65$) and emotional representations (6 items: $\alpha = 0.835$) (see Appendix K).

Gynaecological cancer awareness. Gynaecological cancer awareness was measured by two sections that assessed for knowledge of symptoms indicative of gynaecological cancers and risk factors that increase the likelihood of developing gynaecological cancers (see Appendix F). The development of the symptoms and risk factors awareness scales were informed by previous research into help-seeking for gynaecological cancer symptoms (Forbes et al., 2013; Low, Simon, Waller, Wardle, & Menon, 2013b; Lockwood-Rayermann, Donovan, Rambo, & Kuo, 2009) and risk factors (Bosetti et al., 2012; Evans, Ziebland, & McPherson, 2007; Jemal et al., 2013; Memon, 2009; Rose, 1996; Salehi, Dunfield, Phillips, Krewski, & Vanderhyden, 2008). Each section listed potential symptoms or risk factors and instructed participants to indicate 'yes' or 'no' next to each symptom or risk factor to identify whether they believed each was indeed a symptom or risk factor for gynaecological cancers. The awareness scores for each section were calculated by allocating a score of 1 to each item that participants correctly identified as a symptom of gynaecological cancers, and of 0 for each incorrect response (total possible score 0 - 17). A reliability statistical test revealed reduced reliability for the two scales of symptom (17 items: $\alpha = 0.50$) and risk factor knowledge (20 items: $\alpha = 0.54$) (see Appendix K).

Participants' perception of their personal disease risk was assessed by a comparative risk measure that included three questions placed at the end of the risk factor section of the questionnaire (see Appendix F). The first question asked participants to indicate 'yes' or 'no' to the question, "Have you ever felt at higher risk for disease than others around you?" The following two questions asked participants to describe their perceived risk of developing cancer from when they first sought help (i.e. via GP, emergency services, or another method) to the date of their first visit to secondary care (at the time of participation in the questionnaire study). Participants were asked to indicate whether they felt more at risk of developing cancer than others around them, at similar risk, or less at risk than others. Items were scored from 0 (perception of being less at risk) to 2 (more at risk). A score of 1 indicated that a participant perceived herself to be at similar risk to others. Only the first question was used in the current study analysis to avoid redundancies amongst the variables.

Mood. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; Appendix F) was used as a validated mood questionnaire. The HADS has been used to measure mood in cancer research (Vodermaier & Millman, 2011). Permission to use the HADS in the present research was received by the publisher and distributer (GL Assessment Limited, 2014). To complete the HADS questionnaire, participants indicated responses to fourteen statements relating to depressed or anxious mood over the past week (e.g. 'I feel cheerful'; 'Worrying thoughts go through my mind'). Each statement was scored from 0 (e.g. '[I feel cheerful] Most of the time'; '[Worrying thoughts go through my mind] Very little') to 3 (e.g. 'Never'; 'A great deal of the time'). Outcome scores calculated depression and anxiety into separate subscales that ranged from 0 (normal) to 21 (severe). The reliability statistics showed good reliability for each subscale of Anxiety (7 items: $\alpha = 0.86$) and Depression (7 items: $\alpha = 0.79$) (see Appendix K).

Social capital scale. A shortened version of the Integrated Questionnaire of Social Capital scale (Campbell, Wood, & Kelly, 1999; Grootaert, Narayan, Jones, & Woolcock, 2004; National Centre for Social Research and University College London, 2011; Appendix F) was developed and used to measure five core dimensions of social capital (i.e. neighbourhood belonging and enjoyment, neighbourhood safety/crime, community activity/participation, social support and contacts; Narayan & Cassidy, 2001). The political engagement dimension was removed due to time limitations in clinic and lack of relation to the overall research aims. Social capital was measured using fifteen questions with 'yes' or 'no' as possible responses. Neighbourhood enjoyment and social cohesion was measured by the first six questions of the neighbourhood section (e.g. "Is it a place you enjoy living in?") and included a question measuring the length of time residing in the neighbourhood (ranging from less than 1 year to more than 10). Reliability tests revealed a reduced reliability for this subscale (6 items: $\alpha = .50$) (see Appendix K for reliability tests of each subscale). Crime and safety was measured by the last three questions of the neighbourhood section (e.g. "I have had a personal experience of theft, mugging, break-in or other crime in the last 12 months") and was found to have poor reliability (3 items: $\alpha = -.03$). Community participation was measured by community activity, which also included engagement in religious activities (e.g. "I participated in a voluntary group or local community group in the past fortnight"). The reliability statistic for the community participation subscale revealed reduced reliability (4 items: $\alpha = .21$). Social support was measured by social contacts, using a question that asked the participant to indicate which statement best describes their social relationships out of a possible of four responses (i.e. “close contact with friends and relatives”, “either friends or relatives”, and “no close contact with friends/relatives”). The final question asked participants to identify the number of contacts a participant made with family or friends over the past fortnight. Responses were scored into three groups with four or more contacts scored as 3, two to three contacts scored as 2 and zero to two contacts scored as 1.

Health history questionnaire. Previous health behaviours and beliefs were assessed by a nine-item scale labelled as the health history questionnaire (HHQ) which was informed by DiSipio, Newman, Whiteman, Eakin and Aitken (2006) and assessed aspects of health behaviour in subscales of preventative screenings and examinations, health improving and health harming behaviours, self-perception of obesity, and current comorbidities (Appendix F). Possible responses to each statement were placed on a five-point Likert scale to allow for responses that varied from 1 (‘strongly disagree’) to 5 (‘strongly agree’). The first, second and sixth items of the scale addressed participation in preventative screenings and self-examination behaviour (e.g. “I conduct regular breast self-checking behaviour”), and tests revealed a reduced reliability for this subscale (3 items: $\alpha = .26$) (see Appendix K for reliability tests of each subscale). The second and third items of the HHQ addressed behaviours that aid in improving health (i.e. healthy diet and physical activity) and showed a reduced reliability statistic (2 items: $\alpha = .53$). Items four and twelve addressed health harming behaviours (i.e. smoking and drinking alcohol) and were shown to have poor reliability statistic (3 items: $\alpha = -.42$). The seventh item addressed participants’ perception of their body weight and size (i.e. “My body weight is overweight or obese”), and the eighth item addressed present comorbidities (i.e. “I have a chronic health condition that is different from the condition which has brought me in today”). Items in the scale were developed to suit the target population of post-menopausal women.

Journey to the Clinic and the outcome variable. The ‘Journey to the Clinic’ (see Appendix F) was an open-ended section of the questionnaire designed to follow the theoretical models of the adapted Andersen model of help-seeking (Andersen, Cacioppo & Roberts, 1995) and the SRM (Leventhal, Brissette, & Leventhal, 2003). The first aim of this section was to measure the outcome variable of participants’ time to help-seeking, from when they recognised their symptom to the moment they sought medical help for it (Chapter 5). The second aim of this section was to map the process of help-seeking according the theoretical models (i.e. from recognition, appraisal to help-seeking; Chapter 6), and to describe the overall process of help-seeking for all participants and the differences that exist therein amongst different groups (e.g. obese vs. non-obese, White European vs. non-White European; Chapter 6). The wording and order of the ‘Journey to the Clinic’ section was informed by a review of the help-seeking literature (see Chapter 2) which suggests that symptom recognition begins with the initial detection of bodily change(s) that are subsequently appraised as symptoms of illness. Additional questions were added that identified self-management behaviours engaged in prior to help-seeking (Scott & Grunfeld, 2009) and the different routes to medical help, or ‘methods of help-seeking’ (Public Health England, 2015), according to the Model of Pathways to Treatment (Scott et al., 2013; Walter, et al., 2012).

For the purpose of the present study analysis this section measured the outcome variable of time to help-seeking (see Chapter 6 for further details regarding the Journey to the Clinic questions and flow-chart). The outcome variable of extended time vs. timely help-seeking was defined by calculating the days between the first question on the flow chart (i.e. “When did you first notice your post-menopausal bleeding symptom?”) and the question that asks “What date did you attend your first doctors appointment?”

Outcome variable: Time to help-seeking. Given that delay has not been clinically defined in the context of help-seeking for symptoms of PMB, extended time to help-seeking is defined by increased risk of morbidity with this symptom. It is therefore defined by the clinical recommendation that patients seek help immediately for the symptom of PMB (NICE, 2005), and is supported by the two-week urgent care pathway (Pan Birmingham Cancer Network, 2015). The Center for Disease Control and Prevention (CDCP, 2014) in the United States recommends that individuals should seek help for gynaecological symptoms within two weeks of initial presentation; however, an exception is made for abnormal vaginal bleeding, for which *immediate* care (although not defined) is recommended (Cooper, Polonec, Stewart, & Gelb, 2013). Nevertheless, due to the UK guidelines, extended time to help-seeking is defined in the present study as two or more weeks, as stated above. It should be noted that the outcome variable was calculated from rough estimates provided by participants. Participants provided the date they first recognised their symptom of PMB (referred to as ‘recognition of a bodily change’) and the date they attended their first appointment with a healthcare professional for their symptom of PMB. Approximate estimations were rounded up or down based within two-week increments. For example, if a participant stated that the date in which they sought help or recognised a symptom was in the first couple of weeks of the month, they were encouraged by the researcher to decide if it was in the first week or the second. Otherwise, any range of dates, if greater than two weeks were not included in the study (given that this would skew the data). Therefore, three participants who stated that they recognised their symptoms in “September, 2013”, “The summer, 2014”, and “October, 2014” were not included in the analyses.

The date at presentation of healthcare services includes their first contact with a healthcare provider, which includes attendance at a general practitioner’s, regular cervical screening, comorbidity appointment for another condition or emergency services.

Participants

The total response rate for participants who completed the questionnaire in clinic or at home was 67% (176 out of 264 patients recruited to the study). Of the patients who participated in the study, 65% (*n* = 115) completed the questionnaire in the clinic and 35% (*n* = 61) returned the questionnaires via mail. Of the 176 participants who returned questionnaires 12 did not complete the necessary measures for inclusion in the analysis (i.e. did not complete the outcome measure of time to help-seeking), consequently 164 participants were included in the analysis. Ages ranged from 38 to 85 years (*M* = 58.76, *SD* = 8.96). Many of the women under 50 years of age were not post-menopausal or were medically induced postmenopausal due to hormonal treatment (e.g. breast cancer treatment). Thirty-one women (19% of the sample) measured with a normal BMI (BMI =18.5 – 24.99) and 20% (*n* = 32) women were overweight (BMI = 25 – 29.9). The mean BMI of the sample was 32 (*range* = 19. - 69, *SD* = 8.82), with 41% (*n* = 68) of the participants measuring as obese and 15% (*n* = 25) as morbidly obese (BMI > 39.9). The BMIs of eight participants (5% of the sample) were not measured due to mobility problems (e.g. in a wheelchair). Participants self-reported their ethnicity, with 69% (*n* = 129) of White European ethnic origin, 10% (*n* = 17) of a South Asian/Asian British ethnic origin, 6% (*n* = 10) of a Black African ethnic origin and 1% (*n* = 3) reporting their ethnicity as ‘Other’. Table 5.1 provides an overview of participants’ demographics.

Table 5.1.

Socio-demographic Characteristics of the Sample

		N (n=164)	%	Mean	SD
Age	<50 yrs	15	9.1%	58.76	8.96
	50 - 65 yrs	111	67.7%		
	> 66 yrs	38	23.2%		
Body Mass Index	Normal Weight (BMI = 18.5 - 24.9)	31	18.9%	31.81	8.82
	Overweight (BMI = 25 - 29.9)	32	19.5%		
	Obese (BMI = 30 - 39.9	68	41.5%		
	Morbidly Obese (BMI > 40)	25	15.2%		
	Not measured (due to mobility problems)	8	4.9%		
Level of Education	Less than compulsory	13	7.9%		
	Completed compulsory level	98	59.8%		
	Further/Higher Education	45	27.4%		
	Did no disclose	8	4.9%		
Marital Status	Single	30	18.3%		
	Married	83	50.6%		
	Widowed	22	13.4%		
	Divorced/ separated	24	14.6%		
	Did not disclose	5	3.1%		
Personal Deprivation	None	106	64.6%		
	Minimal	47	28.7%		
	Moderate	8	4.9%		
	Did not disclose	3	1.8%		
Ethnicity	White European	129	68.7%		
	Black African/ Other	13	7.9%		
	South Asian/Asian British	17	10.4%		
	Did not disclose	5	3.1%		
Years Residence in UK	British Born	140	85.4%		
	< 20 yrs	17	10.4%		
	10 - 20 yrs	4	2.4%		
	< 10 yrs	3	1.8%		
Religion	Catholic/Christian	107	65.2%		
	Muslim	3	1.8%		
	Sikh	9	5.5%		
	Hindu	3	1.8%		
	Other	8	4.9%		
	None	27	16.5%		
	Did not disclose	7	43%		
Generations English in Family	Non-English Speaking	4	2.4%		
	First generation	12	7.3%		
	Second generation	15	9.2%		
	All of family English speaking	125	76.2%		
	Did not disclose	8	4.9%		

Note: Missing values were not reported: BMI (*n* = 8); Education (*n* = 9); Personal Deprivation (*n* = 8); Ethnicity (*n* = 6); Marital Status (*n* = 7); Religion (*n* = 7*).*

Clinical investigation outcomes revealed that 50% of the participants (*n* = 80) were discharged from the PMB service after confirmation of a benign biopsy or determination of 'no apparent problem' at their initial visit. The PMB investigations (i.e. pelvic examinations and scans) revealed benign polyp(s) or fibroid(s) in approximately 17% of participants (*n* = 28). For fourteen per cent of participants (*n* = 24) bleeding was due to another problem (e.g. pre-menopausal period bleeding, urinary issues, womb prolapse, atrophic vaginosis, problems with contraceptive coil), or the patient was incorrectly referred to the service prior to stopping hormone replacement therapy. Table 5.2 presents an overview of the sample's clinical outcomes of the PMB examination.

Table 5.2.

Clinical Outcome of PMB Investigation

	N (n=164)	%
Endometrial cancer	8	4.9%
Cervical pre-cancer	1	0.6%
Monitoring ovarian cyst	8	4.9%
Hysterectomy (due to cancer risk)	10	6.1%
Discharged after investigation/benign biopsy	80	48.9.2%
Benign Polyp(s)/ Fibroid(s)	28	17.1%
Discharged due to non-attendance at follow-up	5	3.0%
Other Cause (*e.g. urinary issue, womb prolapse, atrophic vaginosis, problem with coil*)	19	11.6%
Incorrect referral from GP	5	3.0%

Procedure

The data for the present study was collected at two Sandwell and West Birmingham Hospitals NHS Trust sites of City Hospital (from 2 PMB clinics) and Sandwell Hospital (from 3 PMB clinics). The primary method of questionnaire completion was in-clinic during the participant's initial visit to the PMB clinic. Those who did not wish to complete the questionnaire in clinic were given the opportunity to take it home to complete and return to the researcher (S.T.) via post. The researcher was available in clinic to provide assistance in completion of the questionnaire, either by answering questions required for completion or by reading the questionnaire aloud to participants, namely for visually impaired participants or those unable to read written English. Participants who did not speak English were able to use the assistance of a professional interpreter, if available, while waiting for their visit in clinic, or by a family member in clinic or at home.

To improve the questionnaire response rate, follow-up questionnaire packs were sent to participants' homes, if questionnaires were not returned to the researcher within two weeks of a participant's initial clinic visit. The two-week follow-up time was determined to be within a timeframe that did not interfere with the recent recall of the help-seeking process, and was deemed suitable for access to participants prior to diagnosis, given that diagnosis and treatment must begin within sixty-two days from referral to the PMB clinic (NICE, 2005; Pan Birmingham Cancer Network, 2015).

Preparing data for analysis

Reverse coding. Reverse coding was conducted on raw data collected from the IPQ-R and the HHQ. Selected items (Questions 1, 4, 6, 9, 14, 15, 20, 22, 26, 28, 29, 33, 35) of the IPQ-R were reverse coded according to the scoring protocol (Moss-Morris et al., 2002; Weinman, Petrie, Sharpe, & Walker, 2000), and (Appendix F). These items corresponded respectively with the original IPQ-R question order of Timeline 1, Treatment control 23, Timeline 4, Consequences 8, Illness coherence 24, Control 15, Illness coherence 25, Control 17, Timeline 18, Control 19, Emotional representations 36, Illness coherence 26, and Illness coherence 27. Additionally, data from the HHQ (Items 4, 7 – 9) were reverse scored.

Exploring data for outliers and correlation. Descriptive statistics of all variables were conducted in order to examine the present data for possible outliers (see Appendix M). Inevitably, outlying scores were revealed in the data, namely in the outcome variable of time to help-seeking in days, HADS depression scale, IPQ-R consequences sub-scale, waist-to-hip ratio, BMI, categories of ethnicity, HHQ comorbidities subscale, and the Social Capital subscales of neighbourhood belonging, safety and crime, and number of contacts. Most researchers suggest that outliers should be changed and dealt with accordingly to improve the distribution of the data. However, in the current study it was decided that, due to the population and nature of the scales, which are likely to describe a population with variability and extremes, changing the outliers might mask statistical effects and correlations, and ultimately affect the outcome of analyses. Therefore, the data from the present study were not transformed to conform to a normal distribution.

A review of the ethnicity factors revealed that there were not enough participants in each group to use these variables in the analysis (see Appendix N), the ethnicity category was collapsed to include three groups of ethnic categories (i.e. White European, South Asian and Black African/ other). All variables (Appendix E)

All variables were further explored in a correlation matrix to identify any strong, highly significant correlations between them and with the outcome variable to inform imputation of variables into a multiple regression model (Appendix O). From the variables 30 were selected to be included in the analysis. The statistical analysis was supported and conducted by the statistician and psychologist, CJ (as acknowledged in acknowledgments).

Data Analysis Plan

To answer the following research questions, a robust forward stepwise regression model with cross-validation was conducted to identify key predictors of extended time to help-seeking by two-weeks or more.

(a) What are the predictors of delay in help-seeking amongst normal weight, overweight and obese women?

(b) Are there differences between obese and non-obese women regarding time to help-seeking?

An independent sample t-test was conducted to identify potential differences between obese and non-obese women regarding gynaecological cancer awareness.

(c) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ between obese and non-obese women?

A one-way between ANOVA was conducted to compare the effect of ethnicity on gynaecological awareness in White European, South Asian, and Black African/ other ethnicity (see Appendix P).

(d) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ across different ethnic groups?

Finally an independent sample t-test was conducted to identify potential differences in gynaecological cancer awareness between women who extended their time to help-seeking past two-weeks and those who did not.

(e) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ between women who extend time to help-seeking and those who do not?

Results

Statistical analysis

Descriptive statistical analysis revealed a skewed distribution of time (days) to help-seeking from the moment women first experienced a symptom to the moment they sought medical help for their symptom of PMB (range 0 – 3960, *Median* = 13.5; *M* = 136.29, *SD* = 497.30). Out of the total number of participants who provided the outcome variable data (*n* = 164), 43% (*n* = 70) within one week (up to and including 7 days), with 24% (*n* = 39) within three days, 72.6% (*n* = 119) sought help within one month, 13.5% (*n* = 22) sought help between one and two weeks and 27% (*n* = 44) took more than one month to seek help. The outcome variable showed that 51.8% (*n* =85) took two weeks or more (14 days or more) to seek medical help after the detection of PMB. See Appendix M for descriptive statistics to describe scores per measures presented by groups of non-obese and obese women, and ethnic groups of White European, South Asian and Black African/ other as well as descriptive information for women who extended time to help-seeking and those who did not.

Given that nearly a third of the sample took more than one month to seek help (range was from 1 month to 11 years). See the descriptive statistics comparison of groups table presented in Appendix M. Descriptive statistical analyses revealed differences between participants who sought help within two weeks (i.e. timely help-seekers) and those who extended their time beyond one month (i.e. markedly 'delayed'/ extended time) in regards to the acculturation variable, 'Generations of English speaking in the family', such that 82% (*n* = 68) of timely help-seekers identified their family as native English speakers across four generations compared to only 66% (*n* = 33) of markedly extended time to help-seekers.

Predictors of extended time to help-seeking

The second phase of the analysis was concerned with identifying the predictors of time to help-seeking for PMB symptoms amongst women. In order to develop a predictive model of time to help-seeking (in days) the 164 participants were randomly divided into two samples in a 7:3 ratio (Keith, 2006). The larger sample (*n* = 115) was used to estimate the parameters of the regression model, and the smaller sample (*n* = 49) was retained for cross-validation of the predictive model.

Model estimation. Model selection was based upon minimising the Akaike Information Criterion (AIC; Akaike, 1973) and conducted using R statistical analysis software (see Appendix P for R code of regression model analyses). The AIC is a measure of the relative quality of a statistical model for a given set of data. Model selection using the AIC is considered superior to using R^2 as a measure of goodness-of-fit (Spiess & Neumeyer, 2010). This is because the R^2 statistic does not penalise for model complexity. The stepwise algorithm may converge on a model that is over-fitted to the idiosyncrasies of the sample and, as a consequence, shows poor generalisability to novel datasets drawn from the same population. In contrast, the AIC measure stringently penalises for model complexity and, as a result, stepwise regression models developed using this measure of model quality tend to show greater external validity when exposed to validation samples (O'Sullivan & Perr, 2013).

Model estimation was undertaken in two stages. Firstly, the 30 potential predictor variables (see Table 5.3) were entered in a forward stepwise regression model using AIC as the measure of model quality.

Table 5.3.

Potential Predictor Variables Entered into Stepwise Regression

1. BMI

2. Waist-to-hip Ratio

Mood:
  3. Anxiety
  4. Depression

Acculturation:
  5. Years in UK
  6. Generations Of English Language

Ethnicity
  7. White European
  8. Black African/Other
  9. South Asian/Asian British

Illness Perceptions Questionnaire (IPQ):
  10. Timeline
  11. Timecycle
  12. Consequences
  13. Personal Control
  14. Treatment Control
  15. Illness Coherence
  16. Emotional Representation

Social Capital
  17. Neighborhood Belonging
  18. Neighborhood Safety/Crime
  19. Community Activity
  20. Social Support
  21. Social Contacts

  22. Body Shape (BSQ-16A)

Gynaecological cancer awareness:
  23. Risk Factor Knowledge
  24. Personal risk
  25. Symptom Knowledge

Health History Questionnaire (HHQ):
  26. Preventative Health Behaviours
  27. Health Promoting Behaviour
  28. Health Harming Behaviour
  29. Perceived Body Weight
  30. Comorbidities

Outcome Variable:
  2wks or more= extended time to help-seeking

The forward selection algorithm converged on a statistically significant model (F = 20.22; $p < 0.01$) containing four predictor variables. This model had a squared multiple correlation of 0.426, indicating that approximately 42.6% of the variability in extended time to help-seeking could be predicted by the Preventative Health Behaviours, BMI, Neighbourhood Safety/Crime and Emotional Representations of illness (e.g. fear). Table 5.4 reports the parameter coefficients and associated significant tests for this model.

Table 5.4.

Regression Parameters for the Prediction of Extended Time to Reporting for Medical Treatment

	Estimate	Std. Error	t value	Pr(>|t|)
Outcome Variable	-196.617	40.9651	-4.8	5.09E-06
HHQ: Preventative Health Behaviours	143.4061	16.1433	8.883	1.49E-14
BMI	1.5189	0.8233	1.845	0.0678
Social Capital: Neighbourhood Safety	-32.6574	20.8406	-1.567	0.12
IPQ: Emotional Representation	0.8379	1.3874	0.604	0.5472

Table 5.4 demonstrates three variables that are non-significant, because they correlate with each other, however as the p value indicates, they contribute valuable information into the model.

The second stage of model estimation examined the stability of these regression parameters in 5000 bootstrap samples from the estimation data. Within each of the bootstrap samples, the sign of the parameter and the statistical significance of the parameter were recorded. These data are presented in Table 5.5.

Table 5.5.

The Stability of Regression Parameters in 5000 Bootstrap Samples From the Estimation Data

Parameter	% Significant (% of time variable produced change)	% Positive coefficient	% Negative coefficient
HHQ: Preventative Health Behaviours	100	100.0	0.000000
BMI	69.23077	99.70414	0.295858
Social Capital: Neighbourhood Safety	58.87574	0.591716	99.40828
IPQ: Emotional Representation	28.10651	86.39053	13.60947

Preventative Health Behaviours evidenced stable behaviour, producing a statistically significant positive coefficient in each of the 5000 bootstrap samples. BMI and Neighbourhood Safety/Crime demonstrated a high degree of consistency in the sign of the parameter coefficient and both of these parameters were statistically significant in greater than 50% of the bootstrap samples. Despite results showing a positive coefficient in only 86% of the bootstrap samples for Emotion Representation, this parameter was statistically significant in only 28.1% of the samples showing that as emotional representation scores increase (e.g. in representations of fear) extended time to help-seeking increases. Accordingly, as Emotional Representation displayed a high degree of variability, the bootstrap parameter estimates may be responsive to idiosyncratic features of the bootstrap samples and are likely to show poor generalisation. Therefore, the performance of the two models (i.e. the full four variable model and a reduced model with Emotional Representation removed) was assessed in the cross validation sample.

Cross validation. The performance of two models was assessed in the 46 participants reserved for cross validation. The first model contained all four variables from the forward stepwise regression procedure. The parameter coefficients of this model are presented in Table 5.4 and the analysis of variance (ANOVA) and goodness of fit measures (MSE, F and R^2) are presented in Table 5.6.

Table 5.6.

ANOVA and Goodness-of-fit Measures (SE, F and R^2) for the Regression Model Containing HHQ: Preventative Health Behaviours, BMI, Social Capital: Neighbourhood Safety and IPQ: Emotional Representation.

	Degrees of Freedom	Sum of Squares	Mean Squares	F	p(F)	R^2
Model 1	4	168601.09	42150.27	7.24	<0.001	0.545
Error	34	197870.72	5819.73			
Total	38	309425.23				

This model showed a statistically significant prediction of the cross validation sample ($F = 7.24$, $p < 0.01$) and evidenced an R^2 value in excess of that observed in the estimation sample.

The second statistical model only retained the three variables that evidenced a high degree of consistency in their performance within the 5000 bootstrap samples from the estimation data. The parameter coefficients of this model are presented in Table 5.4 and the parameter estimates presented in Table 5.7.

Table 5.7.

Regression Parameters in the Reduced Model for the Predictions of Extended Time to Help-seeking

	Estimate	Std. Error	t value	Pr(>|t|)
(Outcome Variable)	-184.293	36.3471	-5.07	1.58E-06
HHQ: Preventative Health Behaviours	141.1043	15.8863	8.882	1.24E-14
BMI	1.6517	0.8036	2.055	0.0422
Social Capital: Neighbourhood Safety	-32.9664	20.7599	-1.588	0.1151

This model showed a statistically significant prediction of the cross validation sample ($F = 9.24$, $p < 0.01$) and an R^2 value of 0.527, that was minimally different from the complete model reported in Table 5.6 and was in excess of that observed in the estimation sample. See Table 5.8.

Table 5.8.

ANOVA and goodness-of-fit measures (MSE, F and R^2) for the reduced regression model containing HHQ: Preventative health behaviours, BMI and Social Capital: Neighbourhood safety

	Degrees of Freedom	Sum of Squares	Mean Squares	F	p(F)	R^2
Model 2	3	163071.2	54357.08	9.47882	0.000101	0.527
Error	35	200710.4	5734.583			
Total	38	309425.2				

In conclusion, the reduced regression model containing the HHQ subscale of Preventative Health Behaviours, BMI and the Social Capital subscale of Neighbourhood Safety/Crime showed good prediction of the cross validation data of this model and did not reduce the performance of this equation relative to the model containing all four variables. Accordingly, the reduced model should be considered to give the best compromise between parsimony and predictive utility, and its performance in the cross validation sample would suggest excellent generalisability. Surprisingly, findings suggest that an individual's participation in regular preventative health behaviours (e.g. attendance at cervical and breast screenings) and an increase in BMI are predictive of extended time to help-seeking. Furthermore, individuals who perceived a high level of safety in their neighbourhoods sought help sooner than those from neighbourhoods that would be perceived as being high in crime.

Gynaecological Awareness

For the third phase of the analysis, two independent sample t-tests were conducted to compare gynaecological cancer awareness about risk factors and symptoms amongst obese and non-obese women (Appendix P). The results of the t-test revealed that there was no significant difference in symptom knowledge amongst obese (*M* = 10.79, *SD* = 2.57) and non-obese (*M* = 10.85, *SD* = 2.47) women; *t* (158.33) = .16, p > .05. Additionally, a second t-test revealed that there was no significant difference in risk factor knowledge amongst obese (*M* = 12.60, *SD* = 2.85) and non-obese (*M* = 12.88, *SD* = 2.75) women; *t* (159.51) = .62, p > .05. Findings of the t-tests suggest that obese and non-obese women do not differ in their awareness of the symptoms and risk factors of gynaecological cancers.

A one-way between ANOVA was conducted to compare the effect of ethnicity on gynaecological awareness in White European, South Asian, and Black African/ other ethnicities (see Appendix P). There was not a significant effect of ethnicity on symptom knowledge (F (2, 164) = 1.32, p > .05). Additionally, there was not a significant effect of ethnicity on risk factor knowledge (*F* (2, 164) = .441, p > .05). Taken together, these results suggest that an individual's ethnicity does not affect their knowledge of the symptoms and risk factors of gynaecological cancers (Table 5.9a).

Table 5.9a.

Mean and Standard Deviation for Symptom and Risk Factor Awareness Across Ethnicities.

		N	Mean	Std. Deviation	Total Possible Score
Risk Factors	White European	130	12.87	2.619	5
	Black African/ other	11	12.13	2.802	7
	South Asian/Asian British	17	12.20	3.438	5
	Total	158	12.74	2.722	5
Symptoms	White European	131	10.97	2.496	3
	Black African/ other	11	11.22	3.003	6
	South Asian/Asian British	17	10.09	2.399	5
	Total	159	10.89	2.522	3

A descriptive analysis was conducted to identify if differences existed across the groups of obesity and ethnicity in knowledge of obesity as a risk factor. Results found that 71% (*n* = 116) of women in the study were able to correctly identify obesity as a risk factor for the development of gynaecological cancer and 28% (*n* = 46) did not identify obesity as a risk factor.

A chi-square test revealed no significant difference between the groups of obesity in relation to knowledge of obesity as a risk factor for gynaecological cancers (X^2(1, N = 155) = .454, p > .05; Appendix . See Table 5.9b. Furthermore a chi-square test revealed no significant difference between the groups of ethnicity in relation to knowledge of obesity as a risk factor for gynaecological cancers (X^2(2, *N* = 158) = .7054, p > .05; Appendix P).

Table 5.9b.

Knowledge of Obesity as a Risk factor Across Groups of Ethnicities (White European, Black African/Other, and South Asian/Asian British) and Non-obese or Obese.

		Obesity As Risk factor [knowledge]		Total
		Incorrect	Correct	
Ethnicity	White European	33	97	130
	Black African/ other	4	7	11
	South Asian/Asian British	5	12	17
Total		42	116	158
Obese	Non-obese	17	51	68
	Obese/Morbidly obese	26	61	87
Total		43	112	155

A final additional analysis was conducted to compare gynaecological cancer awareness about risk factors and symptoms with extended help-seeking (see Appendix P) using an independent samples t-test. No significant difference was found in symptom knowledge amongst women who sought help within two weeks (*M* = 10.77, *SD* = 2.68) and those who sought help after two weeks (*M* = 10.91, SD = 2.43); *t* (160.42) = -1.86, p > .05. Additionally, there was no significant difference in risk factor knowledge amongst women who sought help within two weeks (*M* = 12.41, *SD* = 2.99) and after two weeks (*M* = 13.18 *SD* = 2.25); *t* (151.84) = -1.86, p > .05. Findings of the t-tests suggest that awareness of symptoms and risk factors for gynaecological cancers does not differ between the women who delay seeking help and those who do not.

Discussion

The present study aimed to: (a) identify predictors of help-seeking for PMB amongst women, to (b) assess for possible differences that exist between obese and non-obese women regarding time to help-seeking, to (c) examine whether awareness about gynaecological cancers (risk factors and symptoms) differ between obese and non-obese women, and to (d) examine whether awareness about gynaecological cancers (risk factors and symptoms) and time to help-seeking differs across ethnic groups.

Summary of Findings

Despite the distinct nature of PMB, nearly half of the sample (49%) took two or more weeks to seek help from a medical professional. The regression model revealed interesting findings suggesting that engagement in preventative health behaviours, increased BMI and participants who lived in neighbourhoods characterised by high crime rates were more likely to extend time to help seeking for PMB. The results of the multiple regression analyses showed excellent prediction of the cross validation data, and the reduced model was suggested to provide the best predictive utility and excellent generalisability.

A surprising predictor variable identified by the regression model suggested that women who regularly attended preventative health screenings were *more* likely to delay seeking help. This finding challenges reports in the literature suggesting that previous attendance at preventative health screenings shortens time to help-seeking (O'Mahony & Hegarty, 2009; Quine & Rubin, 1997). However, these findings may be explained by negative previous interactions with healthcare professionals (HCPs) during screenings, which influence future healthcare utilisation (Gould, Fitzgerald, Fergs, Clemons, & Baig, 2010; Marlow, Waller, & Wardle, 2015) and may discourage future help-seeking for symptoms. Alternative explanations for understanding this association may be that attendance at regular screening programs may be presenting a false sense of safety to women (e.g. women may assume that if there was a problem it would be found at the screening) which inadvertently discourages women from seeking help for additional related symptoms experienced between screening appointments, such that women may wait until their next scheduled screening to raise concerns about new symptoms rather than booking an appointment with their GP.

Moreover, screening services may not be perceived by patients to be an appropriate setting to raise concerns about symptoms. Nevertheless, such results have not been supported in the literature.

The finding that increased BMI predicts extended time to help-seeking parallels previous research in preventative screenings and help-seeking for cancer symptoms, which suggest that obese women are more likely to seek healthcare services at advanced stages of the disease (Arndt, Stürmer, Stegmaier, Ziegler, Dhom, & Brenner, 2002; Maruthur, Bolen, Brancati, & Clark, 2009). However, the relationship between BMI and time to help-seeking is not explained by body image dissatisfaction. Nevertheless, descriptive statistics showed a slightly higher percentage of obese women in the timely help-seeking group (i.e. those who sought help within two weeks) when compared to markedly extended time to help-seeking individuals (i.e. those who took more than one month to seek help). Therefore results may suggest a possible non-linear relationship between the variables of BMI and time-to-help-seeking such that a positive relationship may exist between BMI and time to help-seeking until a certain point, after which point there may be no relationship at all or the relationship may switch directions all together. This may occur at extremes of underweight or morbidly obese women. Alternatively, these seemly contradictory findings may be explained by the skewed distribution of time to help-seeking in the data which suggests a large range of days to help-seeking from zero days to eleven years, with more than half of the sample seeking help within two weeks of detection.

Furthermore, the multiple regression analyses revealed that individuals who reported high levels of safety within their neighbourhoods sought help sooner than those who reported being affected by a personal experience of crime in their neighbourhood. It is known that an association often exists between neighbourhoods with higher crime rates and economically deprived populations (Higgins, Robb, & Britton, 2010). Therefore, this finding may be explained by low socio-economic status and crime that is associated with poorer health literacy, reduced cancer awareness and reduced engagement in healthcare (Boxell et al., 2012; Whitaker, Scott, & Wardle, 2015). Consequently, individuals who experience regular crime in their neighbourhoods are more likely to live in economically deprived areas and are also more likely to experience greater disease morbidity and increased time to help-seeking when compared to those who reside in more affluent areas (Hansen, Olesen, Sørensen, Sokolowski, & Søndergaard 2008; Madison, Schottenfeld, James, Schwartz, & Gruber, 2004; National Cancer Intelligence Network, 2009a; National Cancer Intelligence Network, 2014). This may be due to a prioritisation of competing lifestyle issues and concerns (e.g. maintaining personal safety, financial stability and job security) over issues of health or prevention and encouraging participation in risky health behaviours (e.g. tobacco smoking, unhealthy diet, reduced exercise) (Pampel, Krueger, Denney, 2010). Individuals who live in neighbourhoods characterised by greater social capital (e.g. less crime, greater neighbourhood belonging and enjoyment, available community activities, social support) are more likely to have greater access to health information, increased health literacy (including cancer awareness) and are more likely to access healthcare services (Whitaker, Scott, & Wardle, 2015; Shaw, Egan, & Gillespie, 2007) when compared to individuals with a low social capital.

No differences were found in symptom or risk factor knowledge for gynaecological cancers between ethnicities, and no relationship was found between gynaecological cancer awareness and time to help-seeking. Evidence shows that awareness of symptoms and risk factors for gynaecological cancers did not differ between women who delay seeking help and those who do not. Findings suggested that women were able to identify just over half of the symptoms and risk factors correctly (at 64% and 63% respectively). This low-moderate level of awareness reflects research conducted in ovarian cancer knowledge (Low et al., 2013a). Low public awareness of symptoms of gynaecological cancers are reported in the previous literature (Boxell et al., 2012; Jayde, White & Blomfield, 2010; Low et al., 2013a; Sheikh & Ogden, 1998; Soliman et al., 2008). Nevertheless, findings suggested that more than half of the women were able to correctly identify obesity as a risk factor for the development of gynaecological cancers, and there were no differences in obesity risk knowledge across groups of obesity and ethnicity. Therefore, future research should investigate the awareness of risk factor knowledge amongst a larger sample across the UK.

Limitations and Future Research

The key limitations of the current study include (a) recruitment limitations and questionnaire complexity, (b) methodological issues (i.e. the self-report and retrospective), (c) the inclusion of people who sought help via cervical screening and not at presentation at GP surgeries, (d) the limited sample size, which may not have had sufficient power given the cross-validation sample, and (e) the categorisation of ethnicities into groups.

Due to the exploratory nature of the current study, the questionnaire was complex, covering many different topics in a long questionnaire packet. Inevitably, some questionnaires were returned incomplete. Additionally, limitations exist within the present study, such as the fact that the procedure of completing the questionnaires took place from two different experiential time points (in clinic *prior* to seeing consultant at the PMB service and at home *after* seeing the consultant for PMB). Time of questionnaire completion (before or after clinic appointment) may have affected participants' level of anxiety, and their scores respectively. This is due to reassurance often received from consultants during appointment visits, which may influence women to have more positive illness beliefs after their appointment. Furthermore, the perceived causes and gynaecological knowledge scales may have been influenced by the consultant's explanation of the patient's bleeding and thus may not represent the patient's belief of cause or gynaecological cancer awareness prior to seeking help from the PMB clinic. Nevertheless, each participant was informed by the researcher to complete the questionnaire, recalling the beliefs that they had when they first walked in the PMB clinic door, before visiting the consultant and receiving information about their condition. Furthermore participant questionnaires may have been completed with or interpreted by a family member that was better able to understand English. This lack of structure leaves room for false information to be entered into the questionnaire and includes influences of other individuals' culture, ethnicity, gender specific beliefs and interpretation of language. In summary, a total of 34% (n = 61) of the participant responses were potentially biased by a participant's ability to recall how they felt when they first attended the PMB clinic (within one month of attendance), the findings from the IPQ, and intervening factors involved in completing the questionnaire at home. Nevertheless, as with recall questionnaire studies, each questionnaire is limited by the participant's ability to recall dates.

The objectivity of the outcome measure may be challenged given that they were obtained from self-report estimation dates that were rounded up or down respectively by two weeks, making approximation dates for the beginning, middle and end of the month. Therefore a more objective measure would have been to obtain exact dates from GP record systems and triangulate with estimate s that are rounded to the nearest one or two weeks for *all* participants and map the journey to help-seeking accordingly (by one or two week intervals, rather than using number of days). Nevertheless, these issues are common challenges in help-seeking research, which primarily uses retrospective data collection methods (Scott & Walter, 2010).

Additionally, women who attended the PMB clinic via attending a cervical screening rather than seeking help for a symptom may have affected the findings given that they did not report a concern prior to seeking help, which was developed under the assumption that 'time of concern' would be the first phase of the help-seeking journey, raising questions about the definition the interval of 'detecting or recognising a bodily change'.

Limitations may exist with the sample size, which may not have had sufficient power given the cross-validation sample to include and the unexpected lack of association between many of the variable. Therefore, there may have been variables that were not acknowledged by the multiple regression analysis, due to the subtle relationships and small sample size. Additionally, the study may have benefited from the use of a non-parametric test, however given the exploratory nature of the study given that parametric tests are recommended for both skewed and non-normal distributions and non-parametric tests are recommended when the study is better represented by the median or studies with a low sample size or power. Therefore the multiple regression using AIC was an appropriate analysis for use in the current study. Nevertheless, the results of the study future research should consider the use of a non-parametric test.

Given that the current study did not investigate clinical evidence for the use of this defined time to help-seeking cut-off point, future research should be conducted to investigate the clinical evidence for this definition of delay to identify potential for increased risk of malignancy after a determined number of days post detection of PMB.

The current study revealed that the relationship between BMI and time to help-seeking is not explained by body image dissatisfaction, as suggested by the literature. Therefore, this relationship should be further explored to understand how BMI influences time to help-seeking.

CHAPTER 6: MAPPING THE HELP-SEEKING JOURNEY

Introduction

This chapter presents an additional analysis to the study reported in the previous chapter, and maps the dynamic process and associated behaviours involved in seeking help for PMB symptoms and compares differences in help-seeking across groups (i.e. White European vs. Black, Asian and Minority Ethnic groups (BME); obese vs. non-obese) along specific intervals of the help-seeking journey, from open-ended data provided in the questionnaire.

Literature suggests that individuals engage in numerous self-management behaviours in an attempt to resolve their symptom(s) prior to seeking medical help (Birt et al., 2014; Scott & Grunfeld, 2009; Whitaker, Macleod, Winstanley, Scott, & Wardle, 2015) and that concerns about a symptom must be present for an individual to seek help for symptoms. However, to date, a timeframe has not been identified between concern and help-seeking (Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009; Walter et al., 2012) and no model has been developed to identify the activities and the self-management techniques that women engage in prior to seeking help for potential symptoms of gynaecological cancers.

Previous research has reported that obese (BMI > 29.9) women present later to services with more advanced disease (Arndt, Sturmer, Stegmaier, Ziegler, Dhom, & Brenner, 2002; Maruthur, Bolen, Brancati, & Clark, 2009) and BME groups may delay help-seeking for symptoms of cancer more than White European populations (Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009; Ramirez, Westcombe, Burgess, & Sutton, 1999; Sadler, Jothimani, Zanetto, & Anderson, 2009). Nevertheless, there is mixed evidence on the effect of ethnicity of help-seeking. For example, Trivers et al. (2011) reported a contradictory finding that Black American women were more likely to seek help when they had a personal concern for developing gynaecological cancers.

To the best of our knowledge only one study has been published that maps patients' journeys from recognition of initial bodily change(s) to cancer diagnosis in a qualitative methods study (Molassiotis, Wilson, Brunton, & Chandler, 2010). To date, no visual model has been developed to comprehensively map the journey of help-seeking for PMB and identify possible differences in the journey pathways of different groups (i.e. of various BMIs and ethnicities).

Theoretical Framework

The present study maps patients' journeys to the clinic, primarily according to the Model of Pathways to Treatment (Scott, Walter, Webster, Sutton, & Emery, 2013) and the Self-Regulation Model (SRM; Leventhal, Brisette, & Leventhal, 2003) from the moment women recognised a change or symptom(s) in their body to the moment they sought help for their symptoms and received a referral to attend a PMB clinic. Additionally, this section identifies behaviours that patients engaged in prior to medical help-seeking, the presence of concern and the perceived cause for participants' bodily symptom(s). Nevertheless, the journey to medical help-seeking does not assume nor require an attribution of illness for medical help-seeking to take place, given that some symptoms may be detected at regular appointments for screening or comorbidity management (Scott et al., 2013). This is therefore taken into account by mapping the different routes to medical care. The present study tests the dynamic aspects of the SRM (Leventhal, Brisette, & Leventhal, 2003) at different intervals during the journey and adds additional factors of *self-management behaviour* and *concern*, as identified in the Model of Pathways to Treatment (Scott, Walter, Webster, Sutton, & Emery, 2013).

Aims and hypothesis

The aims of this study were to: (a) map the experience of obese women seeking help for potential symptoms of gynaecological cancers, and to (b) identify whether differences exist between obese and non-obese women and White-European and BME groups regarding time to help-seeking. It is hypothesised that differences will exist between obese and non-obese women and White European and BME groups in time taken along the journey of help-seeking from detection to PMB clinic referral.

Method

Design

The present study was part of the independent measures questionnaire design reported in Chapter 5; a mixed method design was adopted, addressing the last three pages of the questionnaire (Appendix F), which employed open-ended questions and a flow-chart design measure to map the journey of help-seeking for women with PMB, and to explore possible differences in terms of weight and ethnicity amongst groups.

See Chapter 5 Method for information about *Participants, Recruitment* and *Sampling*.

Measures

Journey to the Clinic and Flow Chart. The Journey to the Clinic section of the questionnaire (Appendix F) was developed to follow the structure of the adapted Andersen's Model of Help-seeking (Andersen, Cacioppo, & Roberts, 1995), the principals of the SRM (Leventhal, Brissette & Leventhal, 2003) and the Model of Pathways to Treatment (Scott, Walter, Webster, Sutton, & Emery, 2013; Walter, Webster, Scott, & Emery, 2012). This section employs open-ended questions to comprehensively map a participants' journey to the clinic from the moment they recognised the symptom, became concerned about it, first sought medical help and were referred to the PMB clinic. Additional components were added to the models in the flow chart to allow for assessment of the self-management behaviours that participants engaged in prior to seeking medical help and the different routes individuals took to seek medical help (e.g. General Practitioner surgery, emergency services, gynaecological screenings), according to the Model of Pathways to Treatment (Scott, Walter, Webster, Sutton, & Emery, 2013; Walter, Webster, Scott, & Emery, 2012).

The first question in the Journey to the Clinic section identified the detection of bodily change(s) and asked "When did you first begin to notice that there was a change/symptom(s) in your body?" and "What bodily change did you experience?". To answer the first question, space was provided for participants to fill in the day, month and year. Here, the symptom was broadly defined as the issue/condition that brought the patient into the PMB clinic and was later specified in the flowchart as PMB. Therefore, this initial question allowed participants to develop their own definition of the symptom that was meaningful to their personal experience. The second question addressed concern as a potential reason to discuss the symptom with the healthcare provider (HCP). Concern was measured by asking "When did you first realise that the symptom(s)/changes(s) was something to be concerned about?" Again, the participant was asked to recall the day, month and year that they experienced their concern. If the participant was never concerned about the symptom, or was concerned only after their visit to seek medical advice (e.g. in response to the HCP's concern about their symptom as a risk of cancer), a lack of concern was noted.

The next two pages employ the use of a flowchart to map the dynamic journey to the clinic. The flowchart maps the participants' journey of help-seeking along four time intervals, from the first recognition of a bodily change (i.e. PMB) to recognition of concern (as measured by the previous page), making contact with a HCP to arrange consultation, attending a doctor's appointment and receiving a referral to be seen at the PMB clinic.

Therefore, the journey to the clinic involves appraisal of symptoms, active help-seeking and diagnostic intervals of help-seeking (Scott, Walter, Webster, Sutton, & Emery, 2013; Walter, Webster, Scott, & Emery, 2012).

The first question asked participants to place a date in the box that represents when they first noticed their symptom of PMB. The second question addressed the self-management behaviour that individuals took part in prior to seeking help by asking, "What did you do in response to this? (Select all that apply)". Eleven possible responses (e.g. I looked up the symptom online) were provided, including an open-ended 'other' response. Arrows directed the participant to the next question or corresponding questions relating to the answers selected. For example, if the participant indicated, "I confided in another person" as one of their responses to the second question, they moved to the box marked 2a, where they indicated who they confided in from the seven possible responses provided. Question 3 asked if any of these responses remedied the problem and, if so, for how long. This question was not used in the analysis, as it yielded minimal data, suggesting that most participants indicated that self-management strategies did *not* relieve them of their bleeding symptom.

On the second page of the flowchart, number four of the flowchart asked, "After your initial response to your symptom what did you do?" Three possible responses were provided to map the pathways to secondary care for PMB. Responses included: (a) seeking help from emergency services, (b) booking an appointment with a doctor and (c) other, which allowed individuals to write how they sought help (e.g. at a regular diabetes check-up, at a cervical screening, walk-in clinic). Each response indicated different pathways to medical help-seeking and each mapped distinctive pathways to secondary care (PMB clinic) according to National Institute for Clinical Excellence Guidelines (NICE; 2005) for PMB pathways to treatment. The emergency services pathway asked participants to provide the date of attendance at emergency services, followed by an indication of whether they received a referral immediately from the emergency services to attend the PMB clinic (“yes” or ”no”). If participants indicated ‘no’ for this question, they were asked how many times they had to visit a doctor before they were referred. If a participant booked an appointment through their GP surgery, they were asked to provide the dates (day, month, year) when they contacted the service and attended the booked appointment. The third question for this pathway was identical to the emergency pathway. If participants indicated that they sought help through the third pathway (“other”), an arrow guided participants to the next box that asked, “What route did you take when you sought medical help?” Possible responses included, “booked a doctor’s appointment”, “sought emergency services” or was “referred immediately to post-menopausal bleeding clinic”. If participants were not immediately referred, they were directed by an arrow to answer the referral question described above. The time between the last three time intervals include patient, HCP and system responsibility in time to help-seeking, (e.g. patient’s non-attendance at a scheduled appointment, lack of clinic availability for an appointment, or cancellation of appointments by the clinic or HCP).

Perception of Causes. The Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002; Weinman, Petrie, Sharpe, & Walker, 2000) was used to identify participants’ perceived causes for their PMB symptom according to the SRM (Leventhal, Brissette, & Leventhal, 2003). This was assessed through an open-ended question at the end of the IPQ-R (Appendix F), which asked participants to identify three possible causes of their symptom.

Procedure

See Chapter 5 for detailed description of the questionnaire study procedure.

Data Analysis Plan

Descriptive analyses were conducted to gain an understanding of the patients seeking help for PMB and to provide descriptive and comparative information to understand that processes toward help-seeking for 164 women. This study was developed to be an exploratory mapping study, which measures the time to help-seeking through the dynamic processes between events involved in the journey to medical help-seeking, as reported by participants. Information will be presented using a flowchart diagram that details the time to help-seeking (i.e. timely = within two weeks; extended = two or more weeks) for all participants, and the differences in time to help-seeking across the dichotomised groups of obesity (i.e. obese and non-obese) and ethnicity (i.e. White European and BME groups). The present study answers the following research questions.

(a) Are there differences between obese and non-obese women regarding time to help-seeking?
(b) Are there differences across ethnicities regarding time to help-seeking?
(c) What is the experience of an obese woman seeking help for potential symptoms of gynaecological cancers?

Due to small sample numbers for each of the following minority ethnic groups South Asian/South Asian British (*n* = 17), Black African/ Black British (*n* = 13),the data were further collapsed into dichotomous ethnicity categories of White European and BME. Numeric values for time between events (e.g. symptom detection, concern, help-seeking according to type and receipt of referral for PMB) could not be established in several cases due to incomplete questionnaires returned; hence, this portion of the analysis is limited to those participants who fully completed the journey to the clinic flow chart (*n* = 164). Time between key events was calculated as number of days between events (as time intervals) and many represent estimates provided by patients. Descriptive statistics were calculated and used to report median scores and ranges, namely to account for skewed distributions. The final flowchart reports were reviewed by supervisors for clarity. See Figures 6.1 - 6.3 for flow charts. Additionally, the number of self-management behaviours and the types of self-management behaviours were analysed using frequency tables and descriptive statistics.

Results

To further describe the sample a bivariate cross-tab analysis was conducted to identify possible differences between the variables of ethnicity (i.e. White European and BME) and obesity (i.e. obese vs. non-obese) in relation to BMI. A Chi-square test revealed no significant differences between White European and BME participants and obesity according to BMI ($X^2(1, N = 161) = .012$, $p > .05$). A second Chi-square test revealed no significant differences between White European and BME participants and waist-to-hip ratio ($X^2(1, N = 152) = .035$, $p > .05$). See Appendix Q.

Perceived symptom causes

Twenty-five per cent (*n =39*) of the participants identified their symptom of PMB as caused by a natural aging process, and 20% (*n* = 31) stated that they believed the bleeding was caused by menopause. Eighteen per cent (*n* = 28) stated they didn’t know what was causing their bleeding and 13% *(n* = 20) stated that they believed cancer was the cause. Table 6.1 shows the perceived causes of PMB reported by participants.

Table 6.1.

Perceived Causes for PMB at Time of Secondary Care (PMB Clinic) Visit

	n (N= 154)	%
Natural part of the aging process	39	23.8%
Menopause	31	18.9%
'Don't know'	28	17.1%
Cancer	20	12.2%
Polyps or Fibroids	15	9.1%
Side-effect or complication with medication	14	8.5%
Overweight	13	7.9%
Mood: Stress or depression	13	7.9%
Poor diet/ lack of exercise	11	6.7%
Hormone problems	11	6.7%
Hormone replacement therapy	9	5.5%
Womb prolapse issue	8	4.9%
Side-effect of past surgery (pelvic/ gynaecology surgery/ caesarean)	7	4.3%
Problems with ovaries	7	4.3%
Bladder infection or flu	6	3.7%
No cause	5	3.0%
Problems with cervix	5	3.0%
Other	17	10.4%
Hereditary or bad luck	*4*	*2.4%*
Sexual intercourse	*4*	*2.4%*
Bowel or stomach problem	*4*	*2.4%*
Indication that they are not yet menopausal	*3*	*1.8%*
Back problems	*2*	*1.2%*
Vaginal dryness	*2*	*1.2%*
Diagnosis of breast cancer	*2*	*1.2%*
Never given birth	*1*	*1.2%*
Problem with intrauterine device (i.e. coil)	*1*	*1.2%*
Did not report causes	10	*6.1%*

Self-management behaviour

Sixty-five per cent (*n* = 107) of participants engaged in at least one self-management behaviour prior to seeking medical help for their symptom. Specifically, 32% (*n* = 52) engaged in only one behaviour (*M* = 2.28, *SD* = 1.42.), 31% (*n* = 51) engaged in two self-management behaviours, 27% (*n* = 44) engaged in three to four behaviours and 8% (*n* = 13) engaged in more than four self-management behaviours (see Figure 6.1). More than half

(58%) (*n* = 95) of the participants confided in another person (31% with a family member) before seeking help from medical services (see Table 6.2). Thirty-eight per cent (*n* = 62) monitored their symptoms to see whether they would improve or worsen, and 21% (*n* = 34) sought out advice or information from the Internet. Only one person (.6%) took over-the-counter or alternative medicine in an attempt to relieve them of their PMB symptom(s).

Table 6.2.

Types of Self-management Behaviour Engaged in Before Medical Help-seeking

Self-management behaviour	**n (N= 164)**	**%**
Confided in another person (for advice/support)	95	57.9%
Family member	51	31.1%
Significant other	19	11.6%
Friend	24	14.6%
Pharmacist	3	1.8%
Monitored symptoms to see whether they would improve	62	37.8%
Looked up the symptom online	34	20.7%
Assumed it was normal	23	14.0%
Tried not to think about it	24	14.6%
Assumed it was due to another condition (e.g. diabetes, anaemia)	16	9.8%
Over the counter medicine/ alternative medicine	1	.6%
Altered my diet/ exercise	5	3.0%
Did not indicate self-management behaviours	1	.6%

Method of help-seeking

Each participant was given an option on the flow chart to identify how they sought medical help (i.e. visiting Emergency services, GP surgery or Other). Seventy-seven per cent (*n* = 126) of the participants sought help through their GP surgery, 19% (*n* = 32) sought help through other means (e.g. mentioned PMB to doctor during attendance at regular screening, attendance at healthcare service for other chronic comorbid condition, attendance at healthcare service for other problem) and 4% (*n* = 6) of the participants sought help via emergency services (Appendix Q).

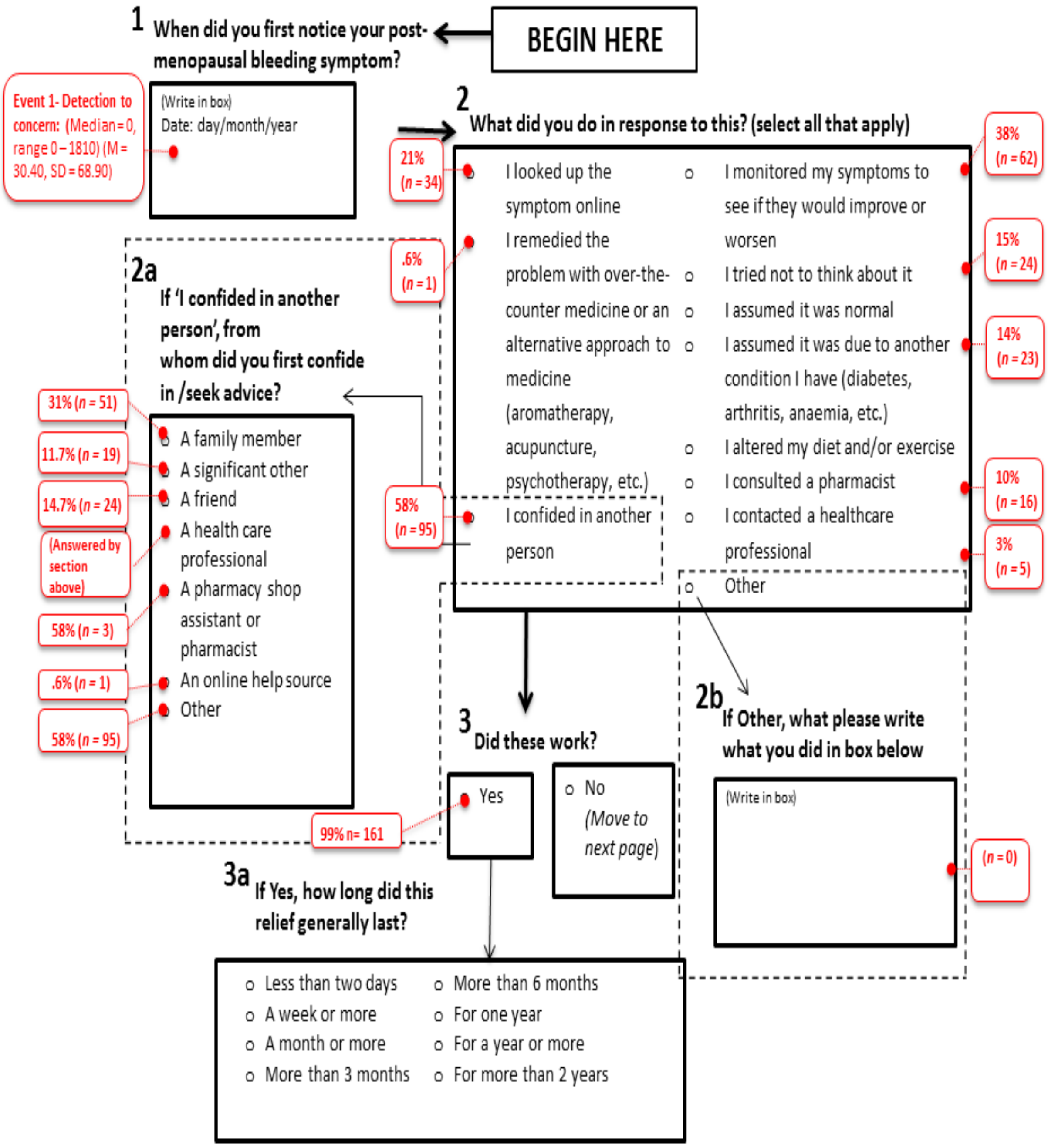

Figure 6.1. Journey to the clinic flow-chart for all participants. (*Continued on next page)*.

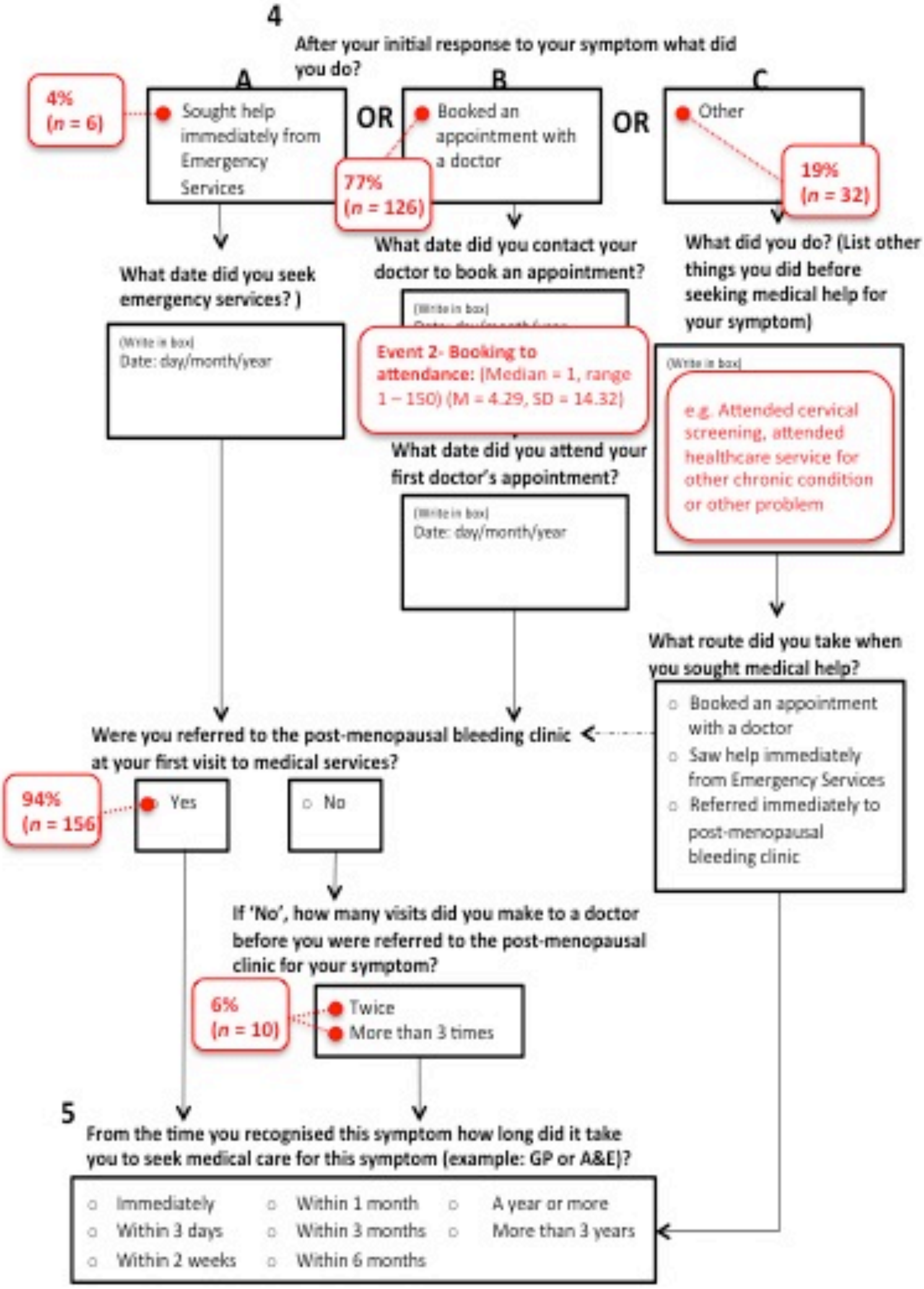

Figure 6.1. [Continued] Journey to the clinic flow-chart for all participants.

Mapping the help-seeking journey: Mapping differences

See Figure 6.1 for flow chart presentation of results from detection of the symptom to referral to PMB clinic. Analyses of variances (ANOVAs) were conducted across all four events to identify differences across methods of help-seeking and the time between each event, however, findings revealed no significant difference (see Appendix R). Therefore, each time interval was mapped regardless of an individual's help-seeking method.

Days from detection to concern. Ninety-one per cent (*n* = 150) of all participants reported that they were concerned prior to contacting a HCP and 12% (*n* = 20) reported that they were not concerned about the symptom prior to seeking help, suggesting that concern is often present before help-seeking, however, that it is *not* essential in the case of seeking help for PMB, particularly for those who sought help via preventative screening (Appendix Q). The total time (in days) from the moment participants detected PMB to the moment they became concerned about the symptom was approximately 30 days (*Median* = 0, range 0 – 1810, *M* = 30.40, *SD* = 68.90; Appendix S). See Figure 6.1. A Chi-square test revealed no significant difference between the groups for the presence of concern before seeking help (X^2 (2, N = 162) = 1.26, p > .05) amongst obese and non-obese women. An independent samples t-test revealed no significant difference in the time from detection to concern for non-obese (*Median* = 0, range 0 - 1810; *M* = 33, *SD* = 214.46) and obese (*Median* = 0, range 0 – 761; *M* = 20.43, *SD* = 90.92) women; *t* (90.46) = .46, p > .05 (Appendix S). See Figure 6.2. Findings suggest that obesity does not play a role in the time it takes to develop concern for the symptom after it is detected and before seeking help.

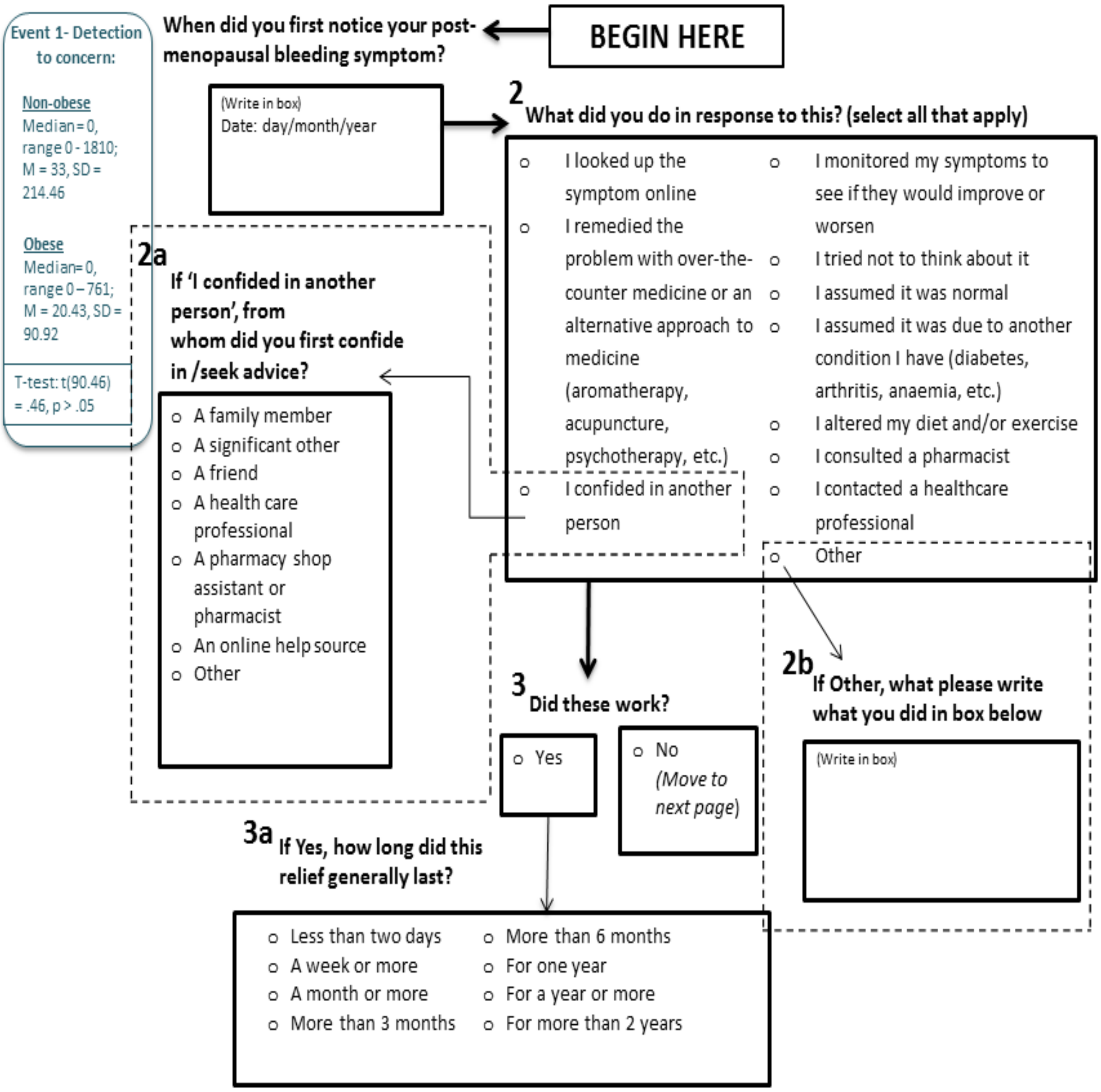

Figure 6.2. Journey to the clinic: Differences between obese and non-obese women.

(*Continued on next page*)

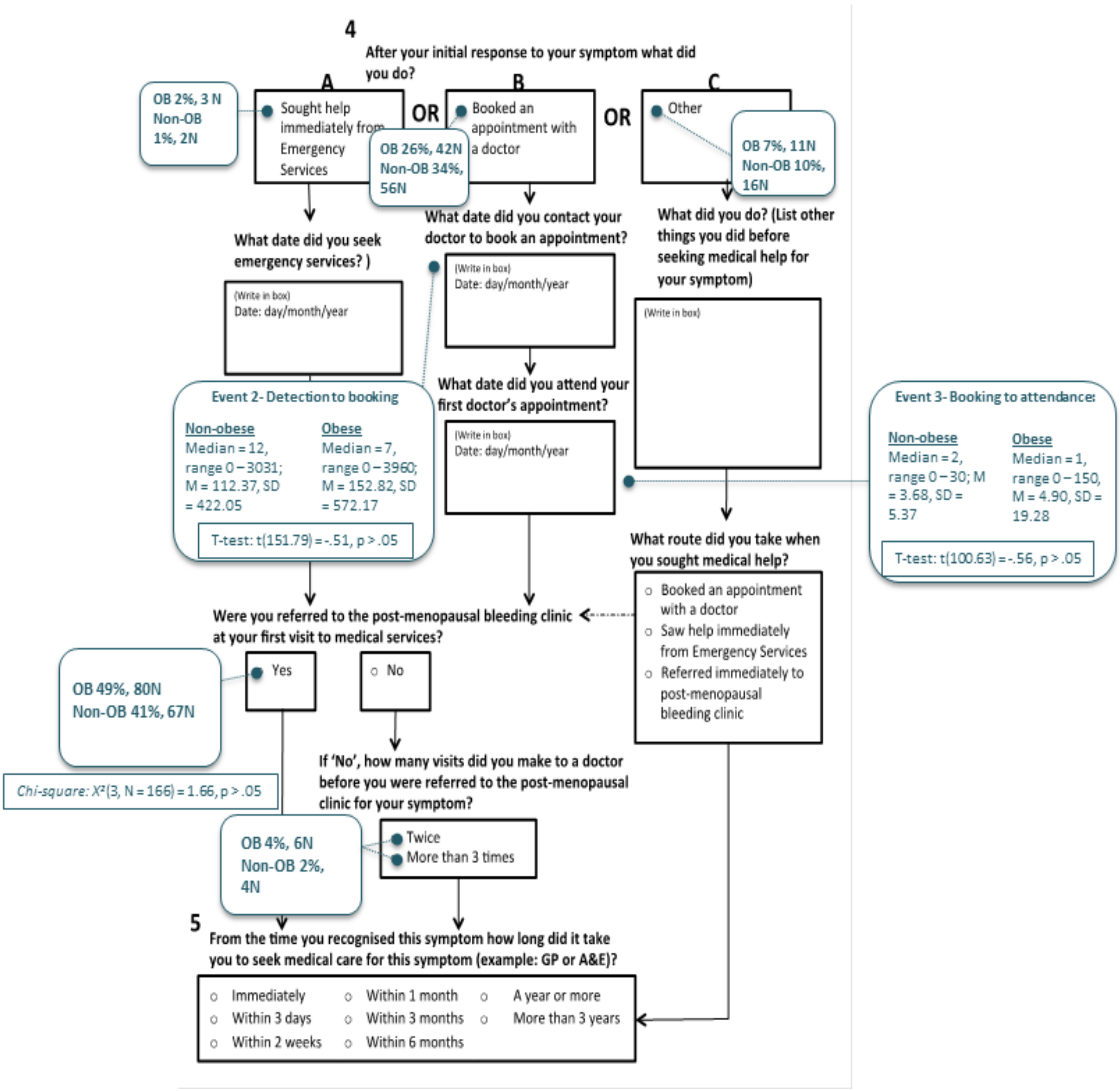

Figure 6.2. [*Continued]* Journey to the clinic: Differences between obese and non-obese women.

A Chi-square test revealed no significant difference between the groups of ethnicity and the presence of concern before seeking help (X^2 (2, *N* = 164) = .54, p > .05). A t-test revealed no significant difference in the time from detection to concern for White European (*Median* = 0, range 0 - 1810; *M* = 27.13, *SD* = 176.84) and BME (*Median* = 1, range 0 – 761; *M* = 48.73, *SD* = 146.96) groups; *t* (50.19) = -.70, p > .05 (Appendix T). Findings suggest that there may be no difference between the two groups of women who identify as White European or BME in time taken to develop concern for the symptom after detection and before seeking help. See Figure 6.3.

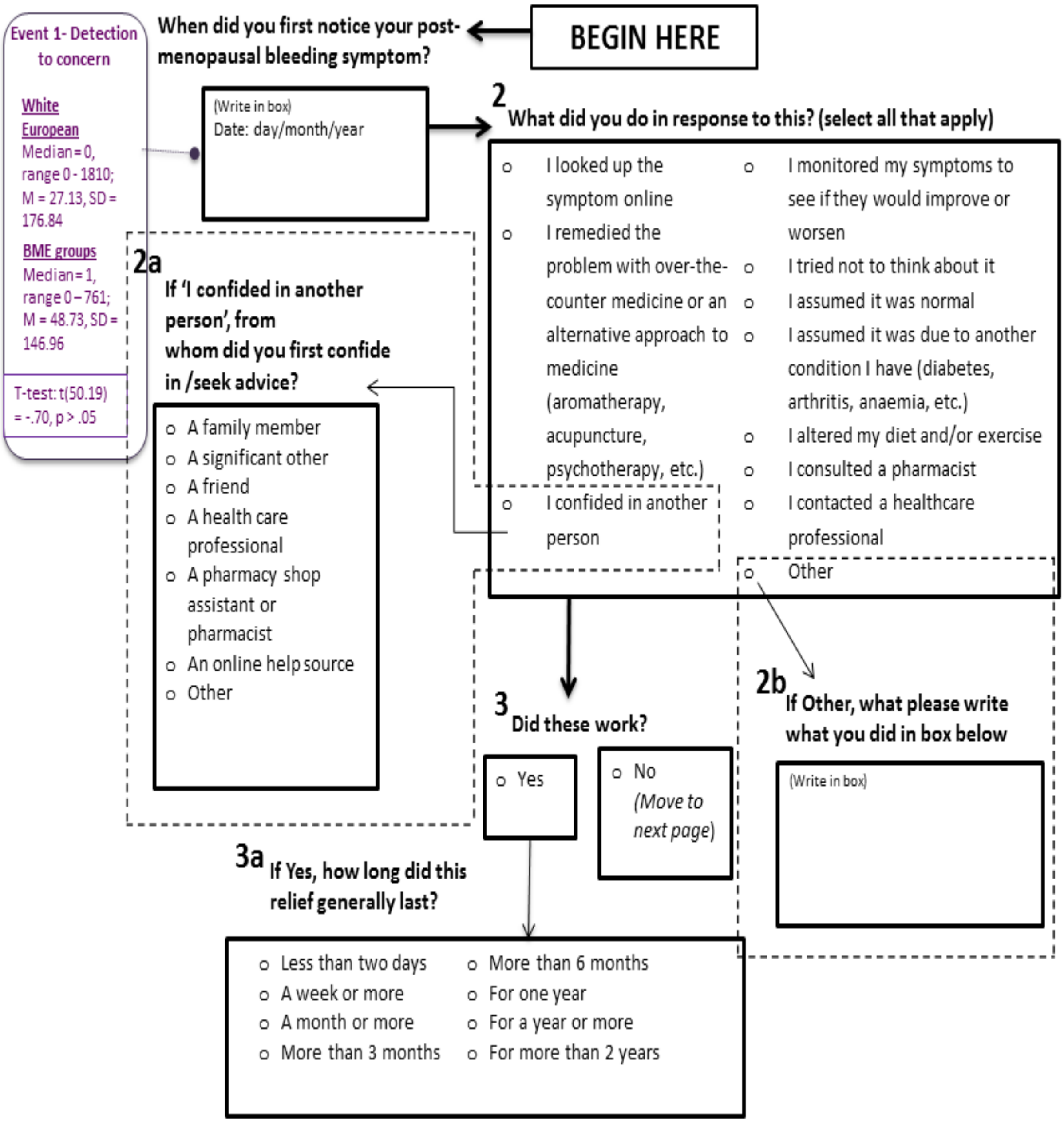

Figure 6.3. Journey to the clinic: Differences between White European and BME groups.

(*Continued on next page)*

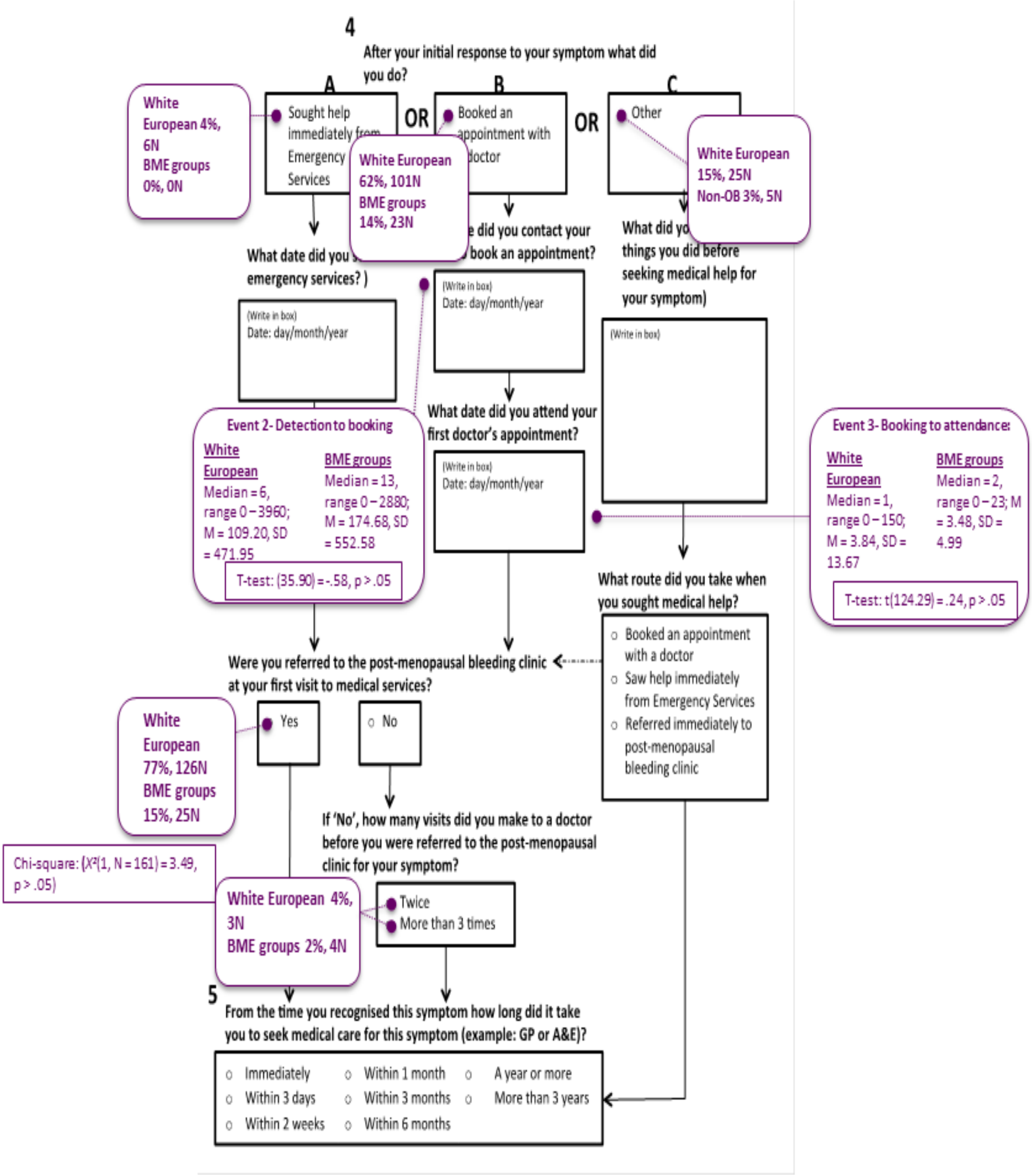

Figure 6.3. [Continued] Journey to the clinic: Differences between White European and BME groups

Days from detection to booking. For all participants, the total time (in days) from the moment they detected their symptom of PMB to the moment they contacted a HCP for an appointment to attend a healthcare service was approximately 130 days (*Median* = 7, range 0 – 3960; *M* = 128.70, *SD* = 496.27; Appendix S; Figure 6.1). An independent samples t-test revealed no significant difference in the time taken from detection to booking for non-obese (*Median* = 12, range 0 – 3031; *M* = 112.37, *SD* = 422.05) and obese (*Median* = 7, range 0 – 3960; *M* = 152.82, *SD* = 572.17) women; *t* (151.79) = -.51, p > .05. (Appendix S; Figure 6.2). Findings suggest that there may be no difference between obese and non-obese women in the time taken to book an appointment with a medical service from the moment in which women detected their symptom of post-menopausal bleeding.

An independent samples t-test revealed no significant difference in the time taken from detection to medical booking for White European (*Median* = 6, range 0 – 3960; *M* = 109.20, *SD* = 471.95) and BME (*Median* = 13, range 0 – 2880; *M* = 174.68, *SD* = 552.58) women*;* *t* (35.90) = -.58, p > .05. (Appendix T; Figure 6.3). Findings suggest that there may be no difference between the two groups of White European and BME (i.e. South Asian, Black Caribbean, Black African, Other Asian) women in the time taken to book an appointment with a medical service from the moment in which women detected their symptom.

Days from booking to attendance to healthcare. For all participants, the average total time (in days) from contacting a HCP to attendance at medical services for their symptom of PMB was approximately four days (*Median* = 1, range 1 – 150; *M* = 4.29, *SD* = 14.32; Appendix S; Figure 6.1). An independent samples t-test revealed no significant difference in the time taken from booking an appointment with a healthcare service and attending the clinic for non-obese (Median = 2, range 0 – 30; *M* = 3.68, *SD* = 5.37) and obese

(*Median* = 1, range 0 – 150, *M* = 4.90, *SD* = 19.28) women; *t*(100.63) = -.56, p > .05 (Appendix R; Figure 7.2) Findings suggest that obesity does not play a role in the time it takes to attend an appointment after booking. This time includes service cancellations, clinic scheduling availability and patient cancelations and non-attendance at scheduled appointments.

A t-test revealed no significant difference in the time taken from booking an appointment with a healthcare service and attending the clinic for White European (*Median* = 1, range 0 – 150; *M* = 3.84, *SD* = 13.67) and BME (*Median* = 2, range 0 – 23; *M* = 3.48, *SD* = 4.99) groups; *t*(124.29) = .24, p > .05 (Appendix T; Figure 6.3) Findings suggest that ethnicity may not play a role in the time it takes to attend an appointment after booking.

Referral from first visit. Ninety-four per cent (*n* = 156) of all participants received an immediate referral upon their first visit to medical services and 6% (*n* = 10) required two or more visits to their medical services before receiving a referral for secondary care (Appendix S; Figure 6.1). Furthermore, the need for two or more visits was only present amongst those who sought help through the method of attending a GP surgery. Therefore, women who attended GP surgery as their method of help-seeking were more likely to need to attend more than once before receiving a referral to secondary care; *t*(155) = 4.467, p = .00 (Appendix S).

A Chi-square test revealed no significant difference between non-obese and obese women regarding the number of visits to a HCP before referral to PMB specialist (i.e. immediate referral, two or more visits) (X^2(3, *N* = 166) = 1.66, p > .05), suggesting that there may be no difference in the number of visits needed to receive a referral to secondary services for obese and non-obese women. See Appendix R and Figure 6.2 for the flow comparison for non-obese and obese women.

A Chi-square test revealed no significant difference between White European and BME groups regarding the number of visits to a HCP before referral to the PMB clinic (i.e. immediate referral/ two or more visits) ($X^2(1, N = 161) = 3.49$, $p > .05$; Appendix T), suggesting that there may be no difference in the number of visits needed to receive a referral to secondary services for the two ethnic groupings. See Figure 6.3.

Discussion

The aims of the present study were to: (a) map the experiences of obese women seeking help for potential symptoms of gynaecological cancers, and to (b) identify whether differences exist between obese and non-obese women and White-European and BME groups regarding time to help-seeking. Participants' journeys to the clinic were mapped using a flowchart to identify: (a) the time between symptom detection and the presence of concern, (b) from detection to contacting medical services for help and (c) from appointment booking to attendance. Despite the minimal differences identified from all events and across both groups of ethnicity and obesity, the mapping study provided an interesting and comprehensive view of the journey to help-seeking, including the presence of concerns most often present prior to seeking help and immediate referrals received from alternative routes to care (i.e. non-GP methods of help-seeking).

Key findings parallel previous literature suggesting that appraisal represented the greatest 'delay' time along the help-seeking journey (Andersen, Cacioppo, & Roberts, 1995; Scott, 2010). Body size was represented similarly across both groups of White European and BME groups. Findings identified no differences across groups of ethnicity (White European and BME groups) and groups of obesity (non-obese and obese women) and time to help-seeking through the three intervals toward help-seeking. Nevertheless, may be due to a floor effect caused by a skewed distribution whereby the mean BMI of the sample was obese or due to the non-normal distribution of days to help-seeking.

This chapter highlighted the complex relationship between BMI and time to help-seeking suggesting an overall non-significant relationship between obesity and time to help-seeking throughout the points to help-seeking. While acknowledging that the t-test used in this chapter is not a as highly sensitive a measure as the previous chapter's multiple regression model, evidence supports the possible explanation for a curvilinear relationship, whereby the relationship between BMI and time to help-seeking may exist up to a BMI threshold (extremes of obesity). Consequently, future research is needed to identify the relationship between BMI and help-seeking for gynaecological cancers, suggesting that future research should employ a design with a stratified sample to account for a curvilinear relationship and the complexities of understanding the relationship between BMI and medical help-seeking.

Additional factors involved in the help-seeking journey

Self-management behaviours. Analysis of self-management behaviours revealed that a majority of women engaged in at least one self-management behaviour prior to seeking medical help for their symptom, with half engaging in two or more behaviours. More than half of the participants confided in another person, most to seek the advice of a family member and some women chose to monitor their symptoms before contacting a HCP. Findings are consistent with the literature suggesting that individuals often engage in multiple self-management behaviours prior to seeking help (Birt et al., 2014; Scott & Grunfeld, 2009; Whitaker et al., 2015) and often seek help only after their attempts to self-manage the symptom(s) have failed (Scott et al., 2013). Findings illustrate the important role of an individual's social milieu and environment in one's decision to seek help, given that individuals may choose to seek help in response to lay advice received from family or friends. Furthermore, the length of time one chooses to spend monitoring a symptom may additionally be influenced by an individual's environment and the context of the symptom interference (Andersen, Cacioppo, & Roberts, 1995; Macleod et al., 2009; Smith, Pope, & Botha, 2005).

Method of medical help-seeking. When choosing to seek help, more than half of the women sought help through their GP surgery and 19% sought help through other means (e.g. mentioned PMB to doctor during attendance at regular screening, attendance at healthcare service for other chronic condition, attendance at healthcare service for other problem), with few choosing to seek help via emergency services. This finding confirms evidence from the literature suggesting that GP surgeries are commonly the first point of contact in medical help-seeking (Public Health England, 2015), although it may not always be the quickest route to care. It is important to note the alternative pathways to care where women received help and immediate referral to secondary care by mentioning their bleeding to a HCP during a routine comorbidity management check or a regular visit to medical services for screening (Scott et al., 2013). Given that the cancer recommendation is to present immediately (NICE, 2005, Cooper, Polonec, Stewart, & Gelb, 2013), findings highlighted the effective use of the urgent referral service from medical services outside of primary care. In acknowledging the small data sample for the emergency services method of help-seeking, future research should investigate help-seeking for gynaecological cancer symptoms through emergency services to assess the experience of help-seeking for PMB via this pathway to secondary care. Nevertheless, it is still recommended that women seek the help of their GP when first experiencing signs of PMB (Public Health England, 2015) to minimise the burden on health resources for PMB pathways to care.

Perceived symptom causes. Findings of the present study revealed that the majority of women did not identify their abnormal bleeding as a warning sign of cancer and many women believed PMB was due to a benign condition (Evans, Zeibland, & McPherson, 2007), or was part of a natural aging process or a side-effect of the menopause (Low, Whitaker, Simon, Sekhon, & Waller, 2015). The study supports previous reports, which suggest that gynaecological cancer symptoms are frequently appraised as benign conditions and not symptoms of cancer (Andersen, Cacioppo, & Roberts, 1995; Cooper et al., 2012; Jones & Johnson, 2012; Whitaker, Winstanley, Macleod, Scott, & Wardle, 2015). Understanding the perception of cause is important to understand what leads women to seek help, given that early detection of most gynaecological cancers is dependent upon women recognising a symptom as meeting sufficient severity (with concern as a reason) to seek medical help (Chapple, Ziebland, & McPherson, 2004; Macleod et al., 2009; Smith, Pope, & Botha, 2005; Quaife et al., 2014; Walter et al., 2012), nevertheless patients' perceived causes may often be in line with the actual diagnosis given that one in ten patients presenting with PMB will receive a cancer diagnosis (Newell & Overton, 2012). This is an important finding given contradictory findings in the literature which suggest that PMB is a distinct symptom, often recognised by women as abnormal and requiring medical attention (Brunswick, Wardle, & Jarvis, 2001; de Nooijer, Lechner, & De Vries, 2002a; Trivers et al., 2008).

Limitations

Non-significant findings may be explained by limitations existing with the methodological choices including timing of the study in the patients' journeys (e.g. estimation dates, not at presentation at GP surgeries, inclusion of attendance at cervical screening and comorbidities rather than help-seeking for symptoms), and the collapsing of ethnic groups.

The study has been limited by the self-report and retrospective nature of the methodology, given that women may have difficulty accurately recalling the length of time it took for them to become concerned about a symptom or to contact healthcare services. To overcome this limitation, the study would have needed to collect data from PMB and GP clinics regarding date of first contact and the number of contacts with the PMB clinic prior to their recent visit, given that previous visits to PMB fast-track the pathway to investigation and diagnosis. This may have provided a more objective measure of time to contacting or visiting healthcare services and would have allowed the number of prior visits to be measured as a factor that may have influenced time to help-seeking. Another option would have been to conduct a prospective study which followed women from the moment they contacted their GP to the moment they were seen at the PMB clinic, given that contacting women at the moment they detect PMB would not be feasible.

Additionally, the current study did not ask individuals who sought help for their PMB via the cervical screening programme if they booked their appointment *after* the bleed or *before*. As such, it could not be determined if the screening was their method of help-seeking for the PMB or a convenience method for a different problem. Nevertheless, it may be assumed that those who had PMB related concern prior to seeking help attended their screening for the primary reason of resolving their PMB concern, however this question will need to be addressed in future help-seeking research to confirm this association and to assess the different methods of help-seeking. Additionally, the inclusion of women who attended the PMB clinic via attending a cervical screenings and incidental help-seeking for a comorbidity rather than seeking help for a symptom may have affected the findings given that they did not report a concern prior to seeking help. This measure was developed under the assumption that ‘time of concern’ would be the first phase of the help-seeking journey, raising questions about the definition the interval of ‘detecting or recognising a bodily change’.

The collapsing of ethnicities into the BME grouping encompasses a variety of cultures, races and religions that exist in the Birmingham and West Midlands region (Office for National Statistics, 2012), which are not distinguished or defined separately in the current study, therefore readers must be cautious when interpreting and generalising findings to wider cultural contexts. Grouping ethnic minorities into one generalisable group can be problematic given that the UK’s ethnic diversity changes geographically throughout the nation. Furthermore the term ethnicity can include additional perceptions of cultural, socio-economic, socio-political and genealogical understandings in it’s definition (Vickers, Craig & Atkin, 2012), and grouping Black, Asian and minority ethnic groups together does not assume homogeneity across these ethnic groups.

CHAPTER 7: THE LIVED EXPERIENCES OF OBESE WOMEN SEEKING HELP FOR POST-MENOPAUSAL BLEEDING- A QUALITATIVE IPA STUDY

Introduction

Previous research suggests that obese women may experience healthcare services differently than normal weight women, proposing that they may have concerns about exposing their bodies to a healthcare professionals (HCPs) due to low body esteem, and they may experience weight-related stigma in healthcare settings (Buxton & Snethen, 2013; Ogden, Clementi, 2010; Phelan, Burgess, Yeazel, Hellerstedt, Griffin, & van Ryn, 2015; Puhl & Heuer, 2008). Given their increased risk of developing gynaecological cancers (e.g. endometrial cancer), it is important to understand the bodily experience of post-menopausal bleeding (PMB) for obese women and to gain knowledge of how these women make sense of their experience from detection of the symptom to medical help-seeking and attendance at secondary care services via the urgent referral pathway.

Qualitative research in this area has focused primarily on the experiences of menopause and has employed different qualitative approaches to understand the biological, psychological and social changes that define this natural and yet complex experience of female midlife. Qualitative research has explored the distressing ways in which women experience menopause with increased levels of anxiety, irritability, angst and depression (Murphy, Verjee, Berner, & Gerber, 2013; Nosek, Kennedy, & Gudmundsdottir, 2012), the emotional responses to aging (Lindh-Åstrand, Hoffmann, Hammar, & Kjellgren, 2007; Nosek et al., 2012; Ogle & Damhorst, 2005) and the great intensity at which the symptoms of hot flushes, night sweats, and vaginal dryness are experienced by women (Hinchliff, Gott, & Ingleton, 2010; Nosek et al., 2012). A study conducted by Ballard, Kuh and Wadsworth

(2001) employed a grounded theory approach to explore the processes of change during the menopause and identified a process that moved from the expectations of menopausal symptoms, to the experience of symptoms, loss of control, a confirmation of menopause, and finally regaining control and experiencing freedom with the cessation of menstruation. The women in this study acknowledged that menopause is a biomedical change, nevertheless, they placed greater importance on the social context in which menopause was experienced, emphasising the social challenges to intimate relationships, family life, friendships and increased work stress caused by menopausal bodily changes.

Qualitative studies have explored the experience of common gynaecological symptoms and the patients' perception of causes (e.g. Low, Whitaker, Simon, Sekhon, & Waller, 2015), such as fibroids (a common cause of PMB). Fibroids are benign tumours on the endometrial lining and often cause symptoms of abnormal or prolonged vaginal bleeding for women of pre-menopausal age (Zimmermann, Bernuit, Gerlinger, Schaefers, & Geppert, 2012). Experiential studies conducted with women diagnosed with fibroids have revealed that women experience feelings of helplessness, fear, anxiety, sadness and defeat at the loss of control and the social restrictions caused by their inability to manage the associated symptom of heavy bleeding (Ghant, Lawson, Sengoba, Recht, Mendoza, McGuire, & Marsh, 2014; Nicholls, Glover, & Pistrang, 2004). In a study that employed grounded theory, Ghant and colleagues (2014) posited that the experience of fibroids might facilitate the development of a negative self-image and concern regarding appearing pregnant, overweight or less attractive. Findings highlighted the negative personal and social impact of fibroids and associated symptoms.

A focus group study explored the experiences of PMB and urgent referral to secondary care for investigation (Tarling, Gale, Martin-Hirsch, Holmes, Kanesalingham, &

Dey, 2013). Each participant in the study (*n* = 15) underwent a hysteroscopy as part of her investigation. The women in the study expressed a fear of cancer was a potential cause for their bleeding, as well as an increased anxiety felt in response to their expedited referral (along the cancer pathway) and a lack of knowledge about the urgent nature of their investigation. Additional findings reported that patients expressed frustration and upset after discharge, which may have been due to a lack of support women that women required after investigation, particularly for those who did *not* receive a cancer diagnosis, suggesting a lack of resolve despite the PMB investigation.

Finally, a study by Arbuckle and colleagues (2014) employed a thematic analysis in a cross-cultural exploration of the PMB experience. Findings revealed that women defined the severity of the symptom by the amount of blood loss and sanitary protection necessary to control the bleeding. Furthermore, findings identified challenges to daily life caused by vaginal bleeding or irregular spotting (e.g. physical activity restrictions, avoidance of sex, embarrassment and anxiety of bleeding through clothing, as well as an avoidance of social engagements due to anxiety about anticipated bleeding and interference with work).

The way in which individuals experience their symptom(s), choose to seek help and interact with healthcare services is an embodied experience that is situated in the context of one’s environment and social world, which consequently shapes how individuals understand their experience. Accordingly, research must understand an individual within their context (Alonzo, 1979; Baumann, 2003; Adams & Salter, 2009) to build a comprehensive understanding of patients’ experiences of help-seeking and utilisation of healthcare services. Larkin, Eatough and Osborn (2011) describe the embodied experience as the way in which we perceive and involve ourselves in and with the world. Authors posit that all experiences are distinctly individual and also global, relational and cultural. Therefore, the decision to seek help often comes when symptoms cause disequilibrium within one's social world (Alonzo, 1984).

Help-seeking for PMB is a complex, dynamic, and highly sensitive process. It is both deeply personal and socially impacting. Despite the more distinct nature of PMB, in comparison with other gynaecological cancer symptoms, literature suggests that while commonly identified by women as abnormal when experienced after the menopause (Brunswick, Wardle, & Jarvis, 2001; de Nooijer, Lechner, & De Vries, 2002a; Trivers, Rodriguez, Hawkins, Cooper, Polonec, & Gleb, 2008), PMB is sometimes misinterpreted as a sign of menopause (Cacioppo, Andersen, Turnquist, & Petty, 1986; Cochran, Hacker, & Berek, 1986) rather than a potential symptom of cancer (Jones & Johnson, 2012).

Given that obese women are at increased risk of developing endometrial cancer, it is important that research explores the unique experiences of obese women with PMB to better understand the help-seeking process and inform practice. The aims of the present study were to explore how obese women experience and make sense of their PMB or abnormal bleeding (for those who were found to not be post-menopausal) and their experiences of seeking help from a PMB specialist clinic via urgent referral.

Method

Participants

Participants included seven obese women (BMI range 36 - 62, *M* = 44.53, *SD* = 10) who sought help for symptoms of abnormal bleeding and were seen by an NHS secondary care PMB clinic in the West Midlands via the urgent referral pathway (see Chapter 5). Ages of the participants ranged from 48 to 61 years of age (*M* = 53, *SD* = 4). Five participants reported their ethnicity as White British (71%); one participant was South Asian Indian and one was Black British. Four participants sought help for their symptom of bleeding within two weeks (range 0 – 305 days, *M* = 56, *SD* = 111). One participant contacted a HCP within two weeks, but waited thirty days to be seen by her GP due to scheduling and personal availability. Three patients were not yet post-menopausal and one patient experienced bleeding and the menopause as side-effects of her breast cancer treatment medication. Three participants sought help via cervical screening appointments and two participants took part in the study upon their second visit to the PMB clinic, therefore they were referred immediately to the PMB clinic without needing to book an appointment at their GP practice. The names of the participants were anonymised via the use of pseudonyms: Sue, Wendy, June, Carol, Michelle, Sharon and Stacy. Please see Table 7.1 for descriptive information of the participants.

Table 7.1.

Table of IPA Participant Descriptives

Participant	Age	Ethnicity	BMI	Time to contacting HCP	Time from booking to attendance	Total time to help-seeking	Method of Help-seeking	Visits to PMB clinic	Investigation results
Sue	52	White British	36	11 days	30 days	41 days	GP practice	1st visit	No apparent problem
Wendy	50	South Asian Indian	54	2 days	0 days	2 days	GP practice	1st visit	No apparent problem
June	61	White British	37	30 days	7 days	37 days	Cervical Screening	1st visit	Pre-cancer /cancer risk
Carol	53	Black British	62	305 days	0 days	305 days	Cervical Screening	1st visit	No apparent problem
Michelle	48	White British	39	3 days	0 days	3 days	GP practice	1st visit	No apparent problem
Sharon	54	White British	46	3 days	3 days	6 days	Cervical Screening	2nd visit	Benign polyps
Stacy	50	White British	39	0 days	0 days	0 days	GP practice	2nd visit	No apparent problem

Recruitment

Participants were recruited via the questionnaire study (Chapter 5; See Appendix G for the Study Design Flow Chart) by indicating on the questionnaire consent form (Appendix I) that they agreed to being contacted regarding participation in a future research study. Consenting participants were selected for the present study by meeting the inclusion criteria of completing the questionnaire study, being within the BMI category for upper level of obesity (BMI > 35.9; WHO, 2000), and having confirmed an absence of a gynaecological cancer diagnosis as an outcome of the recent investigation for of PMB at the Sandwell and West Birmingham Hospitals NHS Trust sites of City Hospital and Sandwell Hospital. The first 19 participants to meet the inclusion criterion were contacted via email, telephone or post using the contact details provided by the participant on the questionnaire consent form (Appendix I). An interview date was scheduled at the time of contact and a patient information sheet for the interview study was provided prior to the interview date (Appendix U).

A total of 76 participants (43.2%) met the inclusion criteria for participation. Of these, only 23 women (13.1% of total N) consented to future participation in the interview study. The first 19 participants to meet the criteria were contacted to participate (10.8% of total N), nine women (5.1% of total N) agreed to participate in the interview study after being contacted by the researcher and interviews were scheduled. Two participants cancelled their interviews and did not reschedule, subsequently a total of seven women participated in the interview study.

The small sample size of the study is reflective of Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) research. The average sample size of IPA studies reported in the literature is $n = 15$, nevertheless, this tends to be skewed by a handful of larger studies, and the typical recommendation for IPA sample sizes falls between five and six or six and ten participants (Smith, 2010; Reid, Flowers & Larkin, 2005). Given this, sampling was chosen to reflect the upper-end of the published recommendation as a way to provide enough evidence for an in-depth development of themes (Smith, 2010; Smith, Flowers, & Larkin, 2009).

Data collection

Before the commencement of interviews each participant was provided with a participant information sheet (Appendix U) and consent form (Appendix V) to read and consent to participate by written signature. Additionally, each participant was verbally reminded about the overall purpose and aims of the study, the open-ended conversational style of the interview, the audio-recording requirement for transcription, confidentiality policies and their right to withdrawal from the study up until one month after participation.

The interview schedule (Appendix W) was developed to explore the unique experiences of obese women seeking help for PMB, the help-seeking process and to understand how participants make sense of their experiences. The process of the interview schedule development underwent an amendment after four interviews were conducted, transcribed and reviewed by the PhD researcher (S. T) and supervisor (M. L) for initial notations, researcher reflections and emerging themes. The first four transcript data highlighted an inflexibility in the interview schedule such that the questioning structure and the many probing questions seemed to interfere with the experiential disclosure during the interviews and did not fully support the flexible and exploratory epistemological stance of an IPA study. Therefore, after discussion of this potential concern with the researcher's qualitative research supervisor (M. L.) it was agreed that further interviews would benefit from a simplified interview schedule to allow for a more open-ended and exploratory approach to the participants' telling of their experiences. Questions regarding specific date recollection were removed, given that they had been previously addressed in the questionnaire study (Chapters 5 & 6) and their interference with the experiential aims. Additionally, the menopausal experience was revealed as an important transitional experience prior to PMB for the first four participants. Therefore, an exploratory question about the menopausal experience (i.e. "Could you please tell me about your experience with menopause?") was added to place PMB in the context of aging.

All interviews took place between 2 and 18 weeks after attending the PMB clinic and upon receipt of investigation of results identifying no diagnoses of cancer. According to the urgent referral pathway buildings (Pan Birmingham Cancer Network, 2015) all patients received results of investigation within two weeks of attendance at the PMB clinic. Interviews were conducted in Sandwell Hospital and City Hospital by the researcher (S. T.), who is a trained phenomenological researcher. Semi-structured interviews were conducted and audio-recorded using a Dictaphone. Participants were invited to bring a partner, close friend or family member to the interview to aid in the recollection of events and to provide support during the interview, however, only direct quotes from the participant were used in the analysis. At the end of each interview, participants were given the opportunity to ask questions or share any additional comments. After completion of the interview each participant was given a debriefing form (Appendix X). Interview times ranged from 44 minutes to 76 minutes *(M* = 55, *SD* = 14.4). Interviews were transcribed verbatim and all names were removed from the transcript to ensure the anonymity of each participant.

Analysis

The study employed the qualitative approach of IPA (Smith, Flowers, & Larkin, 2009), which is an important qualitative approach in health psychology research and was developed to be used specifically in the field of psychological research (Brocki & Wearden, 2006; Todoraova, 2011). IPA is a flexible approach that aims to understand the lived experience of participants and how participants themselves make sense of and attach meanings to their experience.

IPA is a phenomenological, hermeneutic and idiographic approach (Smith & Eatough 2007). The phenomenological aim of IPA is to explore, in-depth, how a particular experiential phenomenon (e.g. an event, process or relationship) is being understood from the person's experiential perspective in a given context and is grounded in Husserl's philosophy of intentionality of consciousness in understanding the meaning of people's experiences (Creswell, 1998). The hermeneutic describes how the phenomenon reveals itself within the context of interpretation, where the researcher's own pre-conceptions are required to make sense of another person's lived experience (Shaw, 2010). Therefore IPA functions to describe the participant's experience as part of a whole lived experience that involves the interactional influences of the social world (e.g. environment, culture) and the interpretations of the participant attempting to make sense of their experience while at the same time the researcher is attempting to make sense of the participant's sense making (Osborn & Smith, 2008). These combined interpretations of meaning create a rich and robust understanding of an experience as well as the significance of the experience to the individual. IPA is idiographic rather than nomothetic as a means of attempting to know in detail what the experience for each person is like and what sense each participant is making of what's happening to him or her. Each case is analysed individually before moving to the next to elicit insights that are commonly overlooked in nomothetic research, which aims to generalise across individuals. Therefore, the IPA approach is an appropriate method to employ in this study as it provides multidimensional rigour to the analysis of health and illness from the patients' perspective

(Biggerstaff & Thompson, 2008) while allowing for reflection and acknowledgement of the relational aspects that influence experience.

A five-step process was followed to analyse each transcript independently before moving onto the next case to repeat these steps and finally establish a master table of themes and super-ordinate themes. The steps performed for each case included reading and re-reading each case multiple times, writing initial notations, developing emergent themes and forging links between themes to establish super-ordinate themes.

Step 1: Reading and re-reading cases. Each case was read and re-read at least three times after transcription. The first two transcripts were reviewed by the researcher's supervisors (M. L. & R. H.) to check for quality and richness of description from each interview. While reviewing each case, the researcher noted first impressions and engaged in free association writing on a separate sheet of paper, paying particular attention to the hermeneutic dialog and careful listening to the interview dynamics.

Step 2: Initial notation. During this step the researcher noted exploratory comments in a free-coding process highlighting significant words, pauses, tense changes and apparent inconsistencies or juxtapositions in the transcription. This was followed by a close, line-by-line analysis and dictation on the transcript to identify *objects of concern,* namely significant concepts, thoughts or things described by the participant and subsequently to describe what the object of concern meant to the participant in comments labelled as *experiential claims* (Larkin, 2014; Larkin et al., 2006). Two additional comment types were used to identify the participant's stance or *positionality* against a whole section or paragraph to understand the participant's narrative tone and mood on a 'global' level (Larkin, 2014). *Researcher reflections* were also dictated to make note of the researcher's questions that arose about her own preconceptions or involvement in the interview, and how these might influence her interpretation of the participant's experience (Larkin, 2014). Comments were further coded using italics, bolded text and underlined words to identify descriptive, linguistic and conceptual content in the previously dictated comments.

Step 3: Emerging themes. To develop emerging themes the researcher engaged in a hermeneutic dialogue between the transcript and comments to assign concise descriptive titles to the meanings attached to the objects of concern.

Step 4: Developing case summaries for theme development. The researcher then created case summaries to highlight an organisation of themes and how they were represented within the data for each participant (Appendix Y).

Step 5: Developing the master table of super-ordinate themes. The researcher developed clear interpretative themes which were subsequently organised into a master table that illustrated the relationships between themes and across cases. Case summaries and the master table were reviewed at different time points by the researcher's supervisors (M. L., R. H. & B. G.) and collaborative changes were discussed and agreed upon to simplify and reduce the number of themes and enhance the organisation of the master table.

Ethics

Ethical approval for the study was granted by the Black Country Committee of the National Research Ethics Service (14/WM/0117) and the Directorate of Research and Development of the Sandwell and West Birmingham NHS Trust (Reference number: 13CAN71) to conduct the study at the sites of City Hospital and Sandwell Hospital in Dudley and Sandwell, West Midlands respectively (Appendix A; see Chapter 5 for full information of Ethics).

Results

Three super-ordinate themes emerged to describe the overall experience of obese women seeking help through PMB clinics with sub-themes used to describe, in detail, the experience of PMB and the process of sense-making each participant engaged in on their journey from detection to secondary care investigation. Super-ordinate themes included: (a) *The ambiguous enmeshment of PMB and the menopause: a dynamic process*, (b) *the investigation as a necessary intrusion* and (c) *the chaotic body*. The ambiguous enmeshment of PMB and menopause was experienced through *the shock* of the bodily change(s), *the paradox of knowing* that describes the fear of knowing and the challenges of facing the unknown. In this ambiguous process the decision to seek help is described as *the penny dropping* moment, and the experience of help-seeking is described through *the tunnel with no end* that reflects the search for an answer to explain one's experience. The investigation as a necessary intrusion describes the patients' experiences with the healthcare service to investigate PMB and includes a preference for *the feminine approach* to medical care and the impact of the *doctor's actions as louder than the words they speak*. The chaotic body is described through the impact of the *shared vs. unique experience* of PMB and the menopause, *exposing the chaos* of the body to outsiders, the *mistrust and hatred of the body*, *the catch-22 of weight-loss and health* efforts, and *the uncertain risk of weight* that was highlighted through discussion of weight-related risks for disease. A detailed table of themes can be found in Table 7.2.

Table 7.2.

Master Table: Superordinate Themes, Sub-themes and Emerging Theme Tables

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1) THE AMBIGUOUS ENMESHMENT OF MENOPAUSE AND PMB
The shock
Why am I bleeding again after so long?
Bleeding is not normal (I shouldn't be bleeding)
Feeling deflated and disappointment
Its not just a period

The paradox of knowing
Wanting to know vs. the fear of knowing
The burden of knowing
Preparing for the worst

The penny dropping
Was fed up
Going obsessed with it all
Oh shit

The tunnel with no end
What's happening to me?
How long is this going to go on?
Searching for the cause
Questions remain unanswered
Without resolve
Unable to close the book/ still up in the air
The problem continues
No-one has the answers
Where do I fit in?

2) THE INVESTIGATION AS A NECESSARY INTRUSION
The feminine approach
The active listener
Old-fashioned understanding
Non-judgmental
The male doctor as dismissive and lacks female understanding

Doctor's actions as louder than the words they speak
Mirror doctor's concern
Fear muffles the information

3) THE CHAOTIC BODY
The shared vs. unique experience
Shared family experience
The side-effect

Exposing the chaos
Internal becomes external
Aging as old and decrepit
The inescapable, uncontrollable, unsolvable
Unprotected outside home
The unpredictable social embarrassment

Mistrust and hatred of the body
The body as an unknown
I hate my weight
I hate my body
View self in disgust

The catch-22 of weight-loss and health
The comorbidity hurdle (e.g. arthritic, asthma, exercise)
Weight-gain as a side-effect
Weight-loss as the struggle

The uncertain risk of weight
Does weight impact gynaecological problems?
How does it impact health?

Ambiguous Enmeshment of PMB and the Menopause: A Dynamic Process

The first theme illustrates an uncertain ambiguity that ties the two experiences of menopause and PMB together in a confusing and enmeshed process. This dynamic process is characterised by complex and continuous ambiguity that keeps resurfacing, hanging on and is never resolved, despite help-seeking and/or completion of the journey through the menopause (i.e. from peri-menopausal to post-menopausal). In this experience many women faced confusion in understanding their bodily experiences and coming to the decision to seek help. Additionally, this sense of confusion continued despite participants' medical help-seeking. The following sub-themes are used to describe the ambiguous and confusing enmeshment of these experiences.

The shock. This sub-theme describes how the initial response to menopause and PMB is met with shock and disappointment when women's expectations of what *should* and *shouldn't* be happening during this time in their lives were challenged.

The excerpt below demonstrates how a participant, Michelle, attempted to make sense of her frightening first encounter with powerful hot flushes during her experience of the menopause.

> *MICHELLE: 'What? What's this?' You know I couldn't understand it. I thought, you know I was having a heart attack or-or, I don't know what I thought. I just thought- I panicked. I had a panic attack, because I didn't know what this was, because I'd never experienced anything that powerful before.*

During a moment of shock, Michelle fears for her life and understands her experience of hot flushes as a heart attack. The shock is accompanied by fearing for the worst.

For PMB, the initial shock of the bleed is made alarming and disappointing when it follows several months without periods. This is because the episode of bleeding suddenly shatters an expectation that women are through the menopause and will no longer need to experience menstruation in their lifetime. An excerpt from Stacy provides a good example of the shock of her PMB and her experience as a stressful disappointment.

> *STACY: I might have gone for months and months and months [...], nothing for- I'm pretty certain it was about a year. And then BANG that happened, and it was heavy. [...] I did find it very very stressful and to be honest when I did have the bleed I was really disappointed, because I thought I'd finished with periods.*

For those who were unsure whether their periods had ended, this period-free time (counted as time from their last period) acted as a temporal gauge for symptom severity and concern. This temporal gauge was necessary to understand severity for those whose bleeding was not accompanied by feelings of being unwell or in pain (more typical signs of symptom severity). Carol described how the only thing concerning about the bleed was the time that existed between her PMB and her previous episode of bleeding.

> *CAROL: I was concerned only because it had been so long since I had seen any bleeding, but I wasn't- I was concerned, but I wasn't.*

Additionally, for both Michelle and Wendy they came to understand that they *shouldn't* be bleeding by comparing their current experiences of bleeding with the quality of their previous periods prior to the menopause.

> *MICHELLE: [...] LOTS of blood. Erm... (sigh) Awful, just AWFUL pain, erm, irritability. You know, just like you would a period, but it was just- it was more severe than a period. [...] Clots about that size [she holds up fingers in the size of a golf ball] coming out you know. Like liver.*

> *WENDY: […] I thought there was something wrong with me, because the blood was like black.*

As you can see from the excerpts above, by comparing the present quality of one's bleed with previous bleeding, and identifying the quantity of time between episodes of bleeding women develop a cognitive method to understand their experience of PMB. This method is then used to develop concern for bleeding as an abnormal symptom.

These excerpts described the shocking experience of menopausal hot flushes and PMB, which often leave women with more questions than answers as they attempt to assess the severity of their symptoms and come to acknowledge the abnormality of their experiences by comparing them to their existing knowledge of the menopause and previous experiences with menstruation.

The paradox of knowing. This sub-theme identifies the paradoxical experience of desiring to make sense of and resolve a bodily concern, the acknowledgment of one's inability to do so, and recognition of the burden that accompanies such knowledge. Women face a conflict between wanting to know what is wrong and the fear of knowing, such that the knowing could be worse than unknowing. Carol demonstrated this conflicting process, in a discussion of how she came to make the decision to seek help.

> *CAROL: Well I wanted to know. I think-I think I wanted to know. I didn't want to know, but I wanted to know. I wanted to know that there was something physically wrong. I don't know-I don't know. I did want to know, and I just wanted, yea, I just wanted to know. That's why I made the decision to come to the clinic and mmm, I did.*

For Carol, this decision to seek help was made after her visit to the GP, where she attended a regular screening and was asked about any recent bleeding. Therefore, for her, the decision to seek help was made by agreeing to attend her appointment at the PMB clinic after being given an urgent referral. Once Carol was able to accept that she wanted to know what was wrong with her body she was able to make the decision to come to the clinic, however, the above excerpt demonstrates the confusing back-and-forth cognitive process that Carol engaged in prior to seeking help. For Sharon, her decision to seek help came once she was able to acknowledge that her desire to know the reason for her bleeding and to resolve the problem had become stronger than the fear of knowing.

> *SHARON: I'd rather have it checked and be told there's nothing than be sitting and wondering and worrying unnecessarily, and just go get it sorted out and then it's finished and you know what it is. Even if it's not very nice you know what it is and you can deal with it whatever way.*

The excerpt from Sharon explains how, regardless of the outcome of the investigation, for her, the benefits of knowing far outweighed the consequences of not knowing what was happening within her body.

Carol further described the fear she experienced once she'd made the decision to take action to seek help, whereby she felt the need to be prepared results of an investigation that would confirm her worst fears.

> *CAROL: I was a bit nervous, yea. A bit nervous, yea, thinking I was going to walk out with the weight of the world on my shoulders. [...] I don't know, I had lots of thoughts didn't I? What was I gonna do? How was I gonna tell people what was going on, and you know, what was gonna happen? How I was gonna pay the bills. You know, I was thinking like all sorts of things, all sorts of things.*

Here, Carol seems to generate the worst-case scenario and begins to prepare to receive information of the terrible unknown. There is a great burden of worry in the future that weighs heavy on her shoulders as she attends her investigation at the PMB clinic.

This subtheme reveals a paradox of knowing that is experienced by women in a dynamic process of attempting to understand their bodily experiences and rationalise their decision to obtain the answers to their questions.

The penny dropping. This subtheme describes a pivotal experience or event that leads to the decision to seek medical help. This experience is defined as the *penny dropping* moment and occurs across the many different personal contexts of bleeding that vary between intermittent, continuous, monthly bleeding and a 'one-off show'. Sharon describes her penny dropping moment in the excerpt below.

> *SHARON: I don't think it's very pleasant. It's- there's lots of different reasons. The mess of it, the embarrassment of it and the fact that you can't control it. And even if you wear underwear that – with pads and stuff it still always manages to get around it somehow. So I had- for the 11 days I had to have two or three towels on me and they- two or three towels on top of me and a shower curtain on top of the bed, you know on top of the bottom sheet. Not because I didn't- I didn't bleed through in the night, but I was frightened to and I think I was going a bit obsessed with it all [...] I think it makes you, well it made me feel dirty, like there's something seriously the matter with me. And then Google it and everything. As soon as you Google it, cancer is the first thing so you start thinking, Oh shit.*

For Sharon the interruption of continuous bleeding in her daily life reached a moment when 'the mess of it, the embarrassment of it and the fact that you can't control it' had become too much for her to bear. There was an all-consuming quality of the bleeding that interfered with all aspects of her life and she became 'obsessed' with the unpredictability of her next bleed. This lack of control and desire to seek out the answers to understand what was happening in her body led her to seek out the Internet as a resource to gain knowledge of the unknown. For Sharon the knowledge of the unknown was shocking when she was faced with the possibility that cancer could be the cause for her bleeding.

The tunnel with no end. To reveal the unknown, women asked the questions ‘what’s happening to me’ (Wendy) and ‘how long is this going to go on’ (Carol). In asking these questions women embarked down a long tunnel to find the answers that could help them make sense of their experience.

Participant June described her initial response to her bleed as an attempt to locate the problem and understand the cause, which was then followed by additional attempts to understand the problem when the rationalised cause did not fit her understanding of what was happening within her body.

> *JUNE: I thought, ‘where’s that coming from’ thinking, ‘have I scratched myself?’ [...][then] I thought it might be a cyst or a polyp or something, because my mum had fibroids many years ago when she was expecting my brother actually. She was in her 30s and I thought, ‘well maybe it’s something like that if it’s a family sort of inherited thing. [...][then] Two or three [times I visited websites], because one of the ones- one of the sites I found, people that had it were still going through the menopause, so I thought, ‘well that doesn’t really apply to me’. So I did have another search to see if I could find sort of- but there wasn’t a lot actually about people that had gone totally through the menopause for several years and then had the symptoms.*

June’s excerpt highlights the dynamic and changing process of trying to find answers that could help her come to make sense of her unique experience. June described how she tried to make sense of her PMB by attempting to physically identify the location and possible acute cause of the bleed, however, when her attempts didn’t yield the appropriate answers she reflected upon her family history as a possible cause. Ultimately she sought out the Internet as a resource to answer her questions, and yet she remained unable to find the answers that could enable her to understand her experience. This inability to make sense of experience by answering the question, "what's happening to me?" led women further down the dark tunnel. Carol described how in trying to make sense of her experience she began thinking of possible causes for her bleed and her thinking became detrimental, quickly turning to thoughts that she may have cancer.

> *CAROL: I was thinking like, I was thinking detrimental really, 'I wonder if I've got cancer'.*

Inevitably, in hopes of ending the search, women turned to knowledgeable HCPs, friends and family members to answer their questions and receive advice on how to relieve them of their unwanted bodily symptoms. Nevertheless, their questions remained unanswered and often symptoms continued despite their seeking medical help.

The excerpt below from Stacy describes how attempts to seek advice from friends were unsuccessful in relieving her symptoms of menopausal hot flushes.

> *STACY: Yea, and I've tried different things [to relieve hot flushes], because all of my friends are 10 and 15 years older than me. We all met as part of a bereavement group and I've had different advice. One's told me to try ginger, cod liver oil, and I've tried everything, and for me nothing works for me at all [to relieve hot flushes].*

For most women there wasn't a complete resolve after seeking medical help, questions remained unanswered, investigation results were unclear or ambiguous, and symptoms continued. Despite receiving results that there was no concern, women did not feel that they were able to 'close the book', leaving them to continue wandering the tunnel and waiting for the end to come. Sue described this experience as a feeling that things are 'still up in the air' as her bleeding continues despite seeking help and receiving results that indicate ‘no apparent problem’.

> *SUE: So really I feel a bit like- still a bit up in the air. I-I know that they took a lining sample and that appeared to be okay. There was a growth or whatever, but they’re not duly worried about that. But that-that’s as far as I am. So I don’t feel like I’ve been able to close the book on that bit. [...] And unfortunately it’s all come back to square one now. However, I’ve been told that there’s nothing horribly wrong down there so. And then you kind of just have to remind yourself that perhaps this will just carry on for as long as it wants to carry on.*

For Sue, she was left to wait until her body ‘wants’ to stop, and she nor a HCP seem to be able to control her body. Furthermore, no indication was provided to suggest how long her body would continue bleeding for, leaving her feeling as though ‘it’s all come back to square one’. This lack of resolve after medical help-seeking was also experienced by women who received confusing or incomplete explanations for their bodily experiences.

In the excerpt below, Carol describes her sustained feeling of confusion even after seeking medical help and receiving an explanation for her PMB from a HCP.

> *CAROL: What they said was that they didn’t think that erm I’d started the menopause yet, because I’m still having bleeds. Erm, and they- what they- the neck of my womb was still too thin or something, or too thick or whatever. So that was a sign that I hadn’t started the menopause [...] Well it’s supposed to mean that I’m still supposed to be having my periods, but I don’t. [...] But I’m not having a proper period as such [...] it’s definitely not regular. I don’t suppose that’s all part of the course?*

For Carol and the other women in this study the definition of ‘the course’ remained unclear and many women found it difficult to identify where their experiences fit into the biomedical stages of the menopause (i.e. peri-menopausal, menopausal, post-menopausal). Another example of this is presented in Sharon's excerpt below, where she expresses her frustration in trying to identify where she fits in with the stages of menopause, given that her experience of help-seeking did not answer key questions of how long she should be experiencing the intermittent bleeding before it would be defined as abnormal.

> *SHARON: All I want to know is are there tests that you can say that, yea, "Yea, you're in the middle. You're coming towards the end." But I don't even know if that exists so. So, but he didn't say it didn't exist, other than, that all we know is when you've completely finished. [...] I think for me I would rather have that kind of information. Erm, but I obviously didn't get it.*

Sharon's excerpt provides an understanding of the complex and often ambiguous stages of the menopause, and the lack of information provided by healthcare services regarding the process and experiences involved in the transition through menopause. During this process many women experienced confusion when attempting to understand their bodily experiences and were unclear about the stage of menopause that they were in. Consequently, they were unable to identify their experience as abnormal. Much of this confusion was reflected in their experiences of coming to a decision to seek help and continued despite medical help-seeking and discharge from investigation, leaving them with unanswered questions (e.g. "how long will this go on for?").

The Investigation as a Necessary Intrusion

This theme describes the female patients' interactions with healthcare services, the impact of the HCP in the experience of help-seeking and the uncomfortable, frightening and at times painful experiences of investigation that are necessary for patients to understand what is wrong inside their bodies and is an essential step toward treatment for their symptom of PMB.

The feminine approach. The first sub-theme describes women's preferences for a female doctor (i.e. General Practitioner) over a male doctor, detailing negative previous experiences where they felt misunderstood or wrongfully dismissed by a male doctor. Women described the feminine approach to care as characterised by active listening, and the ability to empathetically interact with female patients.

Sue described how her experience of feeling dismissed by a male doctor when seeking help for symptoms of menopause influenced her to request a female doctor when seeking help for her recent experience of PMB.

> *SUE: Erm it-it-it probably wasn't, but how it felt was, 'oh it's women's problems it will sort itself out. It's your age, this is what you have to expect'. He probably didn't say that, but that's how it felt- it came across.*

In her experience, Sue perceived the male doctor to be unable to understand her distinctly female experience and furthermore, his approach 'came across' as dismissive of her concern by assuming that it would 'sort itself out' without medical help. This experience emphasised a discomfort that Sue felt with male doctors, which was reflected in her interpretation of her doctor's response to her concern. Sue later described how she experienced the feminine approach to care as more positive and comfortable.

> *SUE: Erm well she actively listened, and she obviously knew more than I did, and she was reassuring, you know, straight away, "Right we'll have these blood tests done, that blood test done".*

Sue's excerpt provides an example of women's preference for a female doctor and a greater sense of comfort with being seen by a female rather than a male, given that a female doctor possesses the capacity to understand and empathise with patients' experiences of being a woman. This is described clearly in June's excerpt below.

> *JUNE: I just thought, I'm more comfortable with a lady doctor [...] Old fashioned I suppose [...] Yea, just to be with somebody that understands what your going through (laugh).*

This sub-theme highlights the important influence that doctors' interactions can have on their patients' help-seeking behaviours, such that women often chose to request a female doctor over a male doctor when booking their appointments for PMB at the GP service.

Doctors' actions as louder than the words they speak. For many women, regular cervical screenings provide an opportunity to raise questions and concerns they may have about their gynaecological health, and for some the results of an investigation may reveal a problem or bodily concern that was not acknowledged by the patient prior to attending the screening. For example, Carol was asked at her regular screening about any bleeding she was experiencing, and about the time since her last period. When she responded that it had been 'about' a year, the nurses who were examining her 'sprung into action' to contact the physician. This left Carol feeling a worrying concern about her PMB that she hadn't felt prior to attending the screening.

> *CAROL: I think they tried to explain to me as plainly as possible that it was nothing to worry about, [...] But I think that the way that things happened it was like, "Oh, that's happened, I need to phone the doctor" and then they phone the doctor and the doctor said, "Refer to the clinic", and [...] I was like just watching all this happening and thinking, 'I wonder if that's like something serious like' sort of thing. So, I went away thinking not really about what they said, but more about what I was thinking about and that it might be something serious and I'm meant to get it sorted.*

Carol's witnessing of the communication between HCPs left an impression of concern that mirrored that of the HCPs'. This concern seemed necessary for Carol to 'get it sorted' and she followed through by attending her secondary services appointment at the PMB clinic. This sub-theme revels the additional importance that is placed on the impact of the doctors' responsive actions and behaviours regarding their concern for a patient's bodily experience (or symptom), whereby the HCP's concern was louder than the words of reassurance they spoke to the patient.

The helping intrusion. As discussed in the first theme, a consideration of the costs and benefits of gaining knowledge during help-seeking is considered prior to seeking medical help, however, the experience of help-seeking involved additional consequences of physical discomfort as a result of examination, and included the psychological challenge of relinquishing one's personal privacy to facilitate investigation toward treatment.

Wendy demonstrated the physical challenges of undergoing a vaginal examination in a dialogue with the researcher during the interview.

> *WENDY: It wasn't nice… It hurts… when they shove it in ya. […] It's all right. I was worried when I first went in. Cause I don't want it [the examination]. I told them I don't want it. They said okay, and I just got over it.*
>
> *RESEARCHER: What made it so that you were able to go through it?*
>
> *WENDY: Do you know, I don't want cancer.*

The excerpt above highlights the importance of examination. Wendy describes how the consequence of her not allowing the doctor to perform the examination would have been much worse (i.e. the possibility of have undiagnosed and untreated cancer) than the physical discomfort and pain she would experience during the examination. Furthermore, the fear of cancer appeared to motivate her to just 'get over it' and endure the examination as worth it, despite the pain and discomfort.

In addition to the physical discomfort of the investigation, Sue described the psychological difficulty of exposing her vulnerabilities to another person in the frightening experience of seeking help for an issue that is ordinarily kept so private in her everyday life.

> *SUE: Opening up into, you know, what is kind of a private side of your life. [...] Not many people find it easy to talk about what's going on with your body and I think the worst thing is when YOU don't understand it. You feel a bit stupid as well... so the worry about opening up to people was frightening.*

Sue describes help-seeking as a challenging experience which requires her to give up her privacy and open up to allow an outsider in to view, touch and make conclusions about a body that was no longer familiar to her. The necessary intrusion is an experience of a patient giving permission to an outsider (the physician) to cause physical and psychological discomfort during an exposure of one's most private self for the primary purpose of gaining an understanding and resolving concerns of a body that had become chaotic and unknown.

The Chaotic Body

The final superordinate theme describes the unpredictable embodiment of symptoms, which is experienced through a chaotic body during PMB and the process through the menopause. The embodied issues of the chaotic body cannot be removed from the context of the aging process, the obese woman's struggle with weight-gain and weight-loss, and the growing distrust or hatred toward their bodies in this view of the body in chaos.

Shared vs. unique experience. In an attempt to understand, distinguish or normalise a body that felt out of control, women often compared their experiences to others. Women shared their experiences of menopause with female family members and described how their experience was different or perhaps more chaotic than others, leaving them to bear their experience alone.

Carol explains how she came to assume that she was menopausal, by relating her experiences of the menopause to those of her family members (i.e. sisters and mother) in the shared 'path' of the menopause.

> *CAROL: I started noticing the change, was probably back in October- November last year when I probably thought, because my sisters were going through it I probably thought I was going through it. So I just assumed that everything that happened [was part of the menopause], because we were all more or less on the same path. Like, 'This has happened'- 'Oh yes I remember this happened', and then the other one would say, 'Nah this has happened' and I would say, 'Oh yea I remember that's happened', because there's only like two years between us all. [...] and my mum said that she went through when she was like in her 50s and whatever, so we just assumed that, you know, everyone was following everyone down. Even my younger sister's gone through it before [...].*

The excerpt from Carol revealed a sense of comfort that she was able to share her experience of the menopause with her family members. Sharing her experience of menopausal symptoms with women who were going through the menopause too, enabled her to feel supported, and their reassurance normalised the changes she was experiencing in her body, perhaps making them feel less chaotic and allowing her to feel less alone in her experience. Contrariwise, Michelle's experience of the menopause was very different from Carol's and she felt that her experience of undergoing breast cancer meant that she experienced the menopause in a more severe and challenging way than those who experienced it naturally (i.e. without the side-effects caused by Tamoxifen treatment).

> *MICHELLE: […] it's vile and like- like I went straight into it. Like other people sort of- if they're not on the Tamoxifen they gradually build up to it, because obviously they're going into the menopause gradually. I went in straight away. So it was like everything just went in, straight away (pshhhoow)!*

For Michelle, her experience of the menopause was unique only to her and she experienced it as a sudden and powerful 'pshhhoow'. With no-one to share her experience with, it felt more sudden and intense, creating a challenge for Michelle who was left to make sense of her experience on her own.

This sub-theme portrays how the shared experience of menopause influenced one's perception of their body by making the experience feel less chaotic and more normal amongst others, while the unique experience of menopause was more chaotic, abnormal, sudden and difficult to endure alone.

Exposing the chaos. This sub-theme describes the exposure of the chaotic body through the menopausal hot flushes and PMB experience. Hot flushes were expressed as inescapable and exposing of women's older age and PMB was experienced as restrictive and threatening to one's ability to be social outside of their home.

Michelle described the unavoidable exposure of her hot flushes that physically exposed her age to outsiders and brought with it a perceived negative judgment that she was old and 'decrepit'.

> *MICHELLE: […] I remember thinking when I was younger, women going through the menopause are like old. […] It's like they're looking at me and thinking, 'Oh God she's old and decrepit' (laugh). […] I don't feel old and decrepit, but other people who haven't been in the menopause, that's how they look at me, as being old and*

> *decrepit. Because I'm going through the menopause. You know, I'm getting hot flushes and because you can see that. You know, you can physically see it.*

Michelle's experience of hot flushes in public places left her feeling misjudged as 'old', and yet she felt unable to defend herself against the evidence of the hot flushes which defined her age as "old and decrepit" to outsiders.

An excerpt from Sue describes a fear that the unpredictable nature of her body could expose her PMB to others in public, leaving her feeling unsafe and unprotected against embarrassment when she was outside the home.

> *SUE: I couldn't do as much as I wanted to do, and then I had to keep nipping back in and out of the house, and when you're somewhere strange, rather than your own home, you-you've got to be protected don't you?*

The excerpts presented in this subtheme revealed women's fears that their chaotic body would be exposed. This fear was interconnected with a feeling of mistrust in the body and it's ability to function properly in the social world.

Mistrust and hatred of the body. Women described the recent development of a hatred toward their larger body size, within the past eight years, due in part to the consequences of age, other illnesses and uncontrollable weight-gain. During this time some women described a loss of trust in their body, which had become unpredictable and unreliable.

Michelle expressed feelings of hatred toward the appearance of her body, which was influenced by her recent weight-gain and the scars left behind after a breast biopsy surgery. Her hatred was further attached to her own loss of control over her body, such that she is no longer able to trust her body to not continue 'falling apart'.

> *MICHELLE: I just hate it. I hate my weight. I hate how I look. I've got scars. […] Just really hate it. I hate my body. […] HATED what- I'd got no control. I've, my feelings, my body was going- just falling apart. It felt as though, 'Ah something else!' You know, what else can go wrong? […] I'm getting a bit teary now [began to cry]… (Giggle).*

The chaotic nature of the menopausal and PMB experiences, in conjunction with other experiences of aging and illness, collectively influenced the creation of a pessimistic emotional sense of the body as no longer trust-worthy. This struggle to cope with a chaotic body that is 'just falling apart' is experienced in frustration and discouragement. In the above excerpt Michelle's weight acts as yet more evidence that her bodily functioning is out of her control.

The catch-22 of weight-loss and health. Participants described a desire to lose weight and an increasing difficulty in losing weight, particularly after the onset of menopause. Women described how their comorbid conditions (i.e. arthritis, diabetes, asthma, hypothyroidism) and the medications used to treat them act as major hurdles to weight-loss efforts. Stacy described a delicate interplay between her managing her asthma and exercising to lose weight, and the conflicting impact of her medication on increased weight-gain. This conflict is described as a frustrating 'catch-22' in her excerpt below.

> *STACY: I'm very aware that with my weight and my shape I can do so much to change it, but then if I start exercising I might make myself ill with my asthma, then I have to go onto steroids. Steroids naturally make me gain weight. So for me it's been like a catch-22. So I've found it very very frustrating.*

The except above explains how despite having the awareness that weight-loss may improve health, the catch-22 of weight-loss and health creates a difficult situation where women are forced to prioritise the two separately. Consequently, treatments for comorbid conditions were prioritised over weight-loss. Health is defined as treating or managing illness and weight-loss is forced to the side as a different priority and a greater challenge.

The uncertain risk of weight. The final subtheme reveals how at the end of the process of help-seeking for gynaecological symptoms and after engaging in the discussion about weight with the researcher, participants seemed to have a low awareness of the impacts of their larger weight or body size on their gynaecological health.

Initially Michelle expresses an awareness that weight-loss may reduce her cancer risk, but in thinking about 'how' it would help she seems to be unable to see how any changes in her weight would help her overall health, given that she feels that she lives a healthy lifestyle defined by eating healthy foods. When describing to the researcher what she could do to reduce her risk of cancer in the future, Michelle stated:

> *MICHELLE: There's nothing-nothing I can do. I can lose weight I suppose. But I have tried, haven't I? I've tried hard haven't I?*
>
> *RESEARCHER: Mmm. And losing weight, what would that do? How would that help?*
>
> *MICHELLE: [long pause] I don't think it would. You know, I eat healthily. So I – you know, I do eat healthily, don't we [looking at husband]? […] So, I think that's the main thing- if you eat healthily. If you eat-you eat healthily then you know, that's a help. But other than that there's nothing you can do. There's nothing… Nothing. Is there? (laugh).*

Similarly, for Carol, when asked by the researcher, "What do you know about weight and risk for diseases?" Carol responded:

> *CAROL: Oh, well the normal ones like erm diabetes and erm, heart attack and stuff like that. I've heard those ones, but nothing else really, and all the ones that can kill yah (laugh).*

Carol's response suggests a low awareness of the life threatening nature of gynaecological cancers and the link between obesity and the development of endometrial cancer, of which PMB is the primary diagnostic symptom.

Despite women's continued desire to lose weight and their unsuccessful attempts to do so, women appeared to lack an understanding of *how* extra weight could impact the development of gynaecological issues and *how* they could approach weight-loss to improve their health and wellbeing.

Discussion

The aims of the present study were to explore how obese women experience and make sense of PMB and their experiences of seeking help from a PMB specialist clinic via urgent referral. The help-seeking journey for PMB was explored using the IPA approach, and revealed novel findings that have not yet been reported by previous qualitative studies on this subject, which described an experiential process of making sense of symptoms and medical help-seeking. Findings highlighted the ambiguous nature of PMB and the menopausal experience that enmeshed the two experiences together in the context of aging and a part of the complex journey through menopause.

The overall experience of PMB is understood as fully embodied, complex, and embedded in a woman's social context, which defines the expectations of what is to occur during midlife. The social context influences symptom perception, appraisal and the decision to seek help (Calnan, 1983; Gold et al., 2000; Pennebaker, 1982; Whitaker, Scott and Wardle, 2015). Women described how the experience of menopausal symptoms *and* PMB carry with them a fear of exposure (e.g. exposing menopause with experiencing hot flushes in public or PMB by bleeding through one's clothes) during social engagements, and influences women's social behaviours, making them feel unsafe whilst outside of their homes (Arbuckle et al., 2014).

The embodied issues of the chaotic body cannot be removed from the context of the aging process, an obese woman's struggle with weight-gain and weight-loss, as well as the growing distrust or hatred toward their bodies in this view of a body in chaos. An important aspect of this distrust was portrayed through women's struggle with weight-loss despite their efforts to live a healthy lifestyle. The 'catch-22' described a conflict between the dichotomous decision to choose to treat comorbid conditions (e.g. diabetes, hypertension, arthritis) over weight-loss, which suggests contradictory definitions of health and weight-loss that do not acknowledge the association between obesity and the development of comorbid diseases (Must, Spadano, Coakley, Field, Colditz, & Dieta, 1999). Therefore, the findings of the present study suggest a lack of knowledge about the benefits of weight-loss (i.e. *how* it can help) in improving health and wellbeing and reducing the risk of developing some cancers, namely endometrial cancer. Nevertheless, despite women's lack of knowledge about the risk factors of obesity and gynaecological cancers (Soliman et al., 2008), and an expressed low body esteem or 'hatred' for their weight, women did not believe that their larger body size or personal body image played a role in their help-seeking experience or time to help-seeking.

Results of this chapter illustrated a dynamic process toward help-seeking which began with the experience of shock and a search to make sense of the experience by identifying the cause and acknowledging severity. In an attempt to make sense of their symptom of PMB, many women chose to self-monitor their symptoms to see whether the bleeding would reoccur in patterns, become heavier or whether pain would develop. Findings suggest that the length of time that women chose to self-monitor a symptom was connected with how women made sense of their bodily change and how they assessed for the severity of their symptoms. It was apparent that assessing for the severity of PMB could pose as a challenge to many women whose symptom was not accompanied with feelings of pain or being unwell. Thus, women engaged in a cognitive comparing process assessing the quality of their current bleed with past bleeds (e.g. periods) and the time since their last menstruation (i.e. pre-menopausal or during the menopause) to conclude if they *should* or *shouldn't* be bleeding. This finding is supported by the illness schema theory of symptoms appraisal (Chapter 2), given that once a symptom is perceived, memories are recalled through an active memory search to enable comparison between the experiencing symptom and the individual's illness schemata (Leventhal, et al., 1997) or past experiences of bleeding. Furthermore, one's illness schema is embedded in dominant lay cultural assumptions about how a body *should* function and how it is experienced in a particular culture (St. Claire, 2003), which is used to understand and make sense of the PMB symptom and is further supported by sociocultural help-seeking literature (e.g. Alonzo, 1979; Hay, 2008; Zola, 1973). Therefore, findings illuminated the importance of understanding women's experiences of PMB within the context of prior menstrual and menopausal experiences.

The process toward help-seeking for these women appeared to be additionally accompanied by an attempt to identify the cause of the bleed. The women who assessed their symptom(s) as a possible sign of cancer, expressed their motivation to seek help with great urgency, which is reported in line with findings from a study by Johnson and colleagues (2011), wherein half of the women who experienced abnormal bleeding were not aware that it was a warning sign for possible cancer and waited more than one month before seeking medical help.

The decision to seek help was preceded by engagement in a paradoxical cognitive process that was characterised by a fear of the unknown, where the decision to seek help is made once the desire to know becomes stronger than the fear of knowing, and the benefits of help-seeking have outweighed the costs. Similar concepts have been described in the literature. For example, in a study investigating barriers to help-seeking for symptoms of ovarian cancer, worries about what the GP might find upon investigation was reported as a key barrier in making the decision to seek help (Low, Waller, Menon, Jones, Reid, & Simon, 2013a). Additionally, in a study by Safer et al. (1979) patients who had imagined negative consequences as a result of their illness, such as imagining themselves on the operating table, took twice as long to seek medical help than individuals who did not have a negative view of the consequences. This fear of the future unknown appears to be a key component in the decision to seek help.

The theme of the penny dropping moment described a key process in seeking help for PMB symptoms. Here, the penny dropping moment acted in parallel or subsequent to the paradox of knowing, and described an instinctual response rather than a cognitive process of decision-making. Here, the symptom experience, which varied between intermittent, continuous, monthly bleeding and a ‘one-off show’, reached a threshold where it became all consuming and intrusive, given that the bleeding was no longer tolerable in daily life. This experience has close links with Alonzo’s (1984) ‘containment theory’ and Cacioppo and colleague’s (1986) ‘threshold of interference’ with daily life, described in Chapter 2. However, the immediacy of the penny dropping moment adds a component that was not discussed in the literature, whereby the experience of this decision was intuitive or emotional in nature and lacked a conscious deliberation into action. Participant's beliefs about when women chose to seek help parallels reports from previous literature suggesting that individuals are motivated to seek help once they are able to acknowledge a symptom as salient enough to reach a threshold of unmanageability in every day life (Macleod et al., 2009; Smith, Pope, & Botha, 2005; Andersen, Cacioppo, & Roberts, 1995).

A study by Tarling et al. (2013) supports the findings of this study that there is a lack of resolve after seeking medical help for PMB, suggesting that women who were discharged from a PMB service after investigation felt frustrated at the lack of information and support they received. In the context of the present study, within Sandwell and West Birmingham Hospitals NHS Trust, each patient is sent an information pamphlet in the post upon receipt of an urgent referral. This pamphlet details the procedures that will be conducted for investigation at the clinic and describes the potential causes and outcomes of the investigation. Nevertheless, the pamphlet does not include information about receiving support *after* investigation and, given the current findings, patients may benefit from receiving additional information after discharge from investigation for women who are told that they are not yet through the menopause. Women who are post-menopausal are informed to self-refer to the clinic if bleeding reoccurs, however those who are not yet post-menopausal are discharged and advised to wait until they are through the menopause (i.e. cessation of bleeding after 12 months). Furthermore, as reflected in the sub-theme 'shared vs. unique experience', it may be beneficial for women to engage in a menopausal support group after discharge as a way for women to provide mutual support and share in their experiences of their complex journeys through the menopause.

During the experience of seeking help, women expressed preference for a female doctor, which has similarly been reported in the literature for gynaecology and women's health (Ekeroma, Harillal, 2003; Gray, 1982; Ludwig, 1999; Makam, Mallappa Saroja, & Edwards, 2010). A UK study conducted by Makam and colleagues (2010) reported that 45% of women in their study preferred a female gynaecologist over a male, reporting 'religious beliefs', 'a better understanding of woman's problems', and issues of 'personal modesty' as some of the reasons for this preference. However, a study by Gray (1982) reported that her patients believed the ability of a doctor to relate to patients on a personal level was more important than their gender, and this included taking a personal interest in the patient, explaining things in detail and taking the time to be with their patients. As such, it is important to emphasise these skills in GP training and practice to ensure positive doctor-patient communication, which encourages future help-seeking behaviours (Amy, Aalbord, Lyons, & Keranen, 2005; Marlow, Waller & Wardle, 2015).

The experience of the investigation at the PMB clinic (secondary care) was described as uncomfortable at best and intrusive, frightening and painful at its worst. Despite the discomfort experienced, the investigation was accepted as a necessary part of resolving one's gynaecological problem. Here, the impact of the HCP's interactions, communications and behaviours with and in front of patients were important factors in the experience of medical help-seeking. In describing these interactions, women revealed 'dismissive' past experiences with male doctors, and the impact of the doctor's 'actions' in front of the patient (Cordingley, Mackie, Pilkington, & Bundy, 2009). The necessary intrusion is therefore understood as an experience of a patient giving permission to an outsider (the physician) to cause physical and psychological discomfort during an exposure of one's most private self for the primary purpose of gaining an understanding of what is happening within her body, and to put an end to the bleeding.

It should be acknowledged that results of the study are not meant to be generalisable to a wider population and may not reflect the experience of obese women as any different than women who are not obese, given that non-obese women may experience similar understandings of symptom perception, appraisal, body image concerns and difficulties losing weight during or after the menopause (Bloch, 2002; Lewis & Cachelin, 2001). Moreover, non-obese women may experience similar concerns regarding help-seeking for PMB, however this was not a comparative, but explorative study and therefore conclusions can only be made as they represent the participants of this study.

Researcher Reflections

I, the primary researcher and author acknowledge the inherent differences that existed between myself and the participants of the study, given that I am a young, non-obese female who has not yet experienced the menopause. Once these differences were acknowledged I aimed to work in a transparent way with the participants, rather than letting this inherent difference create a barrier between myself and the participant. Prior to each interview I explained to the participant that as a researcher I was interested in learning from her, the participant, given that she is the expert on her own experience. I identified a common stance amongst the participants, where upon discussion of the experience of menopause many women described their experience from an expert stance, often phrasing their sentences as if to teach me about what it is to be a menopausal woman, and about what I can expect to experience in the future. Participants often used words like “we”, “us” and “you” the menopause to me. In contrast when women described their experiences of PMB they often had a more experiential stance in describing their own experience as unique from others. Here women often used words to describe the uniqueness of their experience by using words of “I” and “me”.

In discussions surrounding weight and weight-loss it seemed important for participants to describe the many activities (particularly exercise) that they currently engaged in or planned to begin engaging in for weight-loss (e.g. swimming, running, yoga, going to the gym, Zumba). There was a sense that the participants saw me as a health professional and therefore it was important for them to reassure me that they realised the importance of exercise on improving their health as though it was assumed that I would likely advise them to take steps toward weight-loss. On several occasions I reminded participants that I was not a medical professional and was there only to learn about their experience and not to advise or provide information of their condition or concerns. Participants with medical questions or those seeking advice were referred to the clinic nurses after their interview to address any medical questions or concerns.

In the process of data collection I reflected on the personal difficulties I encountered during the initial four interviews in which the structure of the interviews restricted the in-depth exploration of the participants' experiential telling of their PMB and help-seeking journey. Here I did not use the interview schedule in a flexible approach, and the rigidity of the scripted and structured questions (with many prompts) interfered with the flow of the conversation-style interview process. Nevertheless, the first four interviews revealed descriptions of adequate depth and description to allow for inclusion in the study analysis. After alterations were made to the interview schedule to simplify the schedule and remove prompts the flow of the interview went more smoothly and allowed for candid inquiry into the main experiences of the menopause, PMB and help-seeking.

Limitations

A limitation of the study included the heterogeneity of the sample, which included participants in varying stages of the menopause (peri-menopausal, menopausal and post-menopausal), and a woman whose experience of PMB was understood within the context of her breast cancer treatment. The presence of a current cancer diagnosis, while not gynaecological, appeared to greatly influence the interpretation of her PMB experience from the perspective of a patient who had undergone many invasive investigations and treatments over the past year. Nevertheless, whilst acknowledging the differences amongst participants it should be acknowledged that this represents the patient diversity seen in the Sandwell and West Birmingham NHS Trust PMB clinics.

CHAPTER 8: GENERAL DISCUSSION

The present research explored the complex and dynamic journey of help-seeking for potential symptoms of gynaecological cancers and accessed a high-risk group (i.e. obese women) currently underrepresented in the published literature for help-seeking behaviour amongst individuals experiencing symptoms of cancer. The thesis provided a novel and comprehensive view of the experience and journey to help-seeking and findings challenged previous assumptions in the literature about the relationships between obesity, preventative screenings and delayed help-seeking for symptoms.

Thesis Aims and Summary of Findings

The overall aim of the thesis was to advance our knowledge and understanding of help-seeking for symptoms of gynaecological cancers and to identify whether obesity is associated with time to help-seeking. Research built an understanding of the experiences and processes of help-seeking for obese women and assessed for the possible differences across groups of obese and non-obese women as well as White-European and Black, Asian or minority ethnic (BME) groups in time to help-seeking and awareness of gynaecological cancers. This was achieved by answering the following research questions:

(a) What can we learn about help-seeking from the perspective of healthcare professionals (HCPs)? (Chapter 4)

(b) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ between obese and non-obese women? (Chapters 4 & 5)

(c) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ across different ethnic groups? (Chapters 4 & 5)

(d) Do knowledge and beliefs about gynaecological cancers (i.e. risk factors and symptoms) differ between women who extend time to help-seeking and those who do not? (Chapter 5)

(e) What are the predictors of delay in help-seeking amongst normal weight, overweight and obese women? (Chapter 5)

(f) Are there differences between obese and non-obese women regarding time to help-seeking? (Chapter 5 & 6)

(g) Are there differences across ethnicities regarding time to help-seeking? (Chapter 6)

(h) What is the experience of an obese woman seeking help for potential symptoms of gynaecological cancers? (Chapter 6 & 7)

The thesis provided a unique perspective from HCPs to adapt practice to meet the specific needs of obese patients and highlighted a belief that obese women are more likely to delay medical help-seeking for gynaecological cancer symptoms. Our mixed methods research findings supported previous literature that suggests a low awareness of the symptoms and risk factors of gynaecological cancers (Boxell et al., 2012; Sheikh & Ogden, 1998; Jayde, White & Blomfield, 2010; Low, Waller, Menon, Jones, Reid, & Simon, 2013a; Soliman et al., 2008) and mixed evidence revealed a limited understanding of the links between obesity and the development of some cancers, namely gynaecological cancers (Soliman et al., 2008), and a lack of knowledge regarding *how* weight-loss can reduce their risks for cancer (see Chapters 5 & 7). No disparities were found in gynaecological cancer awareness, and a low awareness was reflected across groups of obese and non-obese women, as well as White European and BME groups. Findings showed that increased body mass index (BMI) was associated with extended time to help-seeking along with living in high crime neighbourhoods, and surprisingly, regular attendance at preventative screenings. Additionally, no differences were found across ethnicities regarding time to help-seeking. Overall, the present thesis highlights a complex relationship between obesity and help-seeking and provides an understanding of how obese women experience and make sense of their complex transition through the menopause to post-menopausal bleeding (PMB), and the fully embodied experiences of PMB from detection of a bleed (i.e. *the shock)* to secondary care investigation (i.e. *the necessary intrusion*).

Despite the distinct nature of PMB, nearly half of the sample took two or more weeks to seek help from a HCP. Findings paralleled previous literature, suggesting that appraisal represented the greatest 'delay' time along the help-seeking journey (Andersen, Cacioppo & Roberts, 1995; Scott, 2010), which may be partially associated with a non-appraisal of abnormal bleeding as a warning sign of cancer and thus appraising bleeding as a benign or non-serious condition (Andersen, Cacioppo & Roberts, 1995; Cooper et al., 2012; Evans, Zeibland and McPherson, 2007; Jones & Johnson, 2012), and recognition of irregular bleeding as a part of the natural aging process (e.g. side-effect of the menopause) (see Chapter 7). However, the study with HCPs highlighted that often it is not only the patients that misinterpret the symptoms, but also the HCPs' who interpret the vague symptoms of gynaecological cancers as benign or due to weight-related issues (e.g. bloating, changes in bowel habits, back pain). This possible misinterpretation of symptoms may extend the time to help-seeking and referral (Macleod et al., 2009; Smith, Pope, & Botha, 2005). Consequently, findings confirm results from previous research suggesting that appraisal of symptoms is a key process along the help-seeking journey, and that HCPs play an important role in early detection and providing prompt pathways to treatment. It is important that research identifies the factors that are likely to influence individuals to extend their time to help-seeking, thereby increasing morbidity of disease, particularly amongst those at higher risk for disease.

Findings further suggested that HCPs may hold misconceptions, namely suggesting that obese women are more likely to delay medical help-seeking for potential gynaecological cancer symptoms than normal weight women, highlighting that HCPs perceived obese women to face physical, psychological, social and economic barriers to help-seeking. Differences emerged between the HCPs' reported beliefs about barriers to care for obese women and the perception from the women themselves. For example, HCPs reported perceived barriers to care consistent with previous research suggesting that a larger body size and body dissatisfaction would pose as barriers to women choosing to seek help for potential symptoms of gynaecological cancers (Amy, Aalbord, Lyons, & Keranen, 2005; Ridolfi & Crowther, 2013). However, the patient interview study in Chapter 7 did not support this perception, showing that women did not believe that obesity played a role in their time to help-seeking. Nevertheless, both patients and HCPs identified concerns with embarrassment in exposing one's body during examination (Szymonia, Cwiek, Berezowska, Branecka-Wozniak, Dziobek, & Malinowski, 2009).

Further evidence from both obese women and the HCPs who work in direct care with them, revealed an important lack of awareness for gynaecological symptoms and risk factors, namely the links between obesity and the development of gynaecological cancers (Soliman et al., 2008). HCPs largely overestimated the perceived barriers to help-seeking for obese women experiencing potential symptoms of gynaecological cancers, however, they may have underestimated the number of obese patients seeking gynaecological cancer care services, which was reflected in the non-stratified sampling of the study that revealed more than half of the participants were obese compared with the estimated 30% from HCPs.

Mixed methods results revealed a limited awareness of the gynaecological symptoms and risk factors of cancer, a limited understanding of the association between obesity and the development of cancers and a lack of knowledge regarding *how* weight-loss improves health and reduces risks for disease. Increasing gynaecological awareness, suggestions for future research and intervention will be addressed in greater detail in a later section of this chapter.

Addressing barriers to help-seeking. Results from the multiple regression analyses suggested that BMI predicts extended time to help-seeking, and hence parallels previous research conducted on utilisation of preventative screenings and help-seeking for cancer symptoms, which suggest that obese women are more likely to seek healthcare services at more advanced stages of the disease (Arndt, Stürmer, Stegmaier, Ziegler, Dhom, & Brenner, 2002; Maruthur, Bolen, Brancati, & Clark, 2009). However, contradictory findings from analyses conducted as part of Chapters 5 and 6 suggest a more complex and potentially curvilinear relationship between BMI and time to help-seeking, such that a positive relationship between BMI and time to help-seeking may exist until a certain point, after which point there may be no relationship at all. This may occur at extremes of underweight or morbidly obese. Additionally, findings may have been skewed by the distribution of BMI amongst the sample, given that the mean BMI was obese. Finally, findings may be skewed by the distribution of time to help-seeking in the data which suggests a large range of days to help-seeking from zero days to eleven years, with more than half of the sample seeking help within two weeks of detection.

The relationship between BMI and time to help-seeking is not explained by body image dissatisfaction, despite the correlation between BMI and body image, and the results reported do not provide evidence to suggest that body image dissatisfaction is a predictor of help-seeking, particularly given that women distinctly stated that their weight had not influenced their time-to-help-seeking (Chapter 7). Nevertheless, increasing BMI may lead women to feel less comfortable about exposing their bodies, thereby creating a more negative experience of healthcare services, which has been shown to act as a barrier to help-seeking (Amy et al., 2005). Despite previous research suggestions that body dissatisfaction and embarrassment of size may be responsible for this delay (Amy et al., 2005; Ridolfi & Crowther, 2013), this association may be less to do with BMI and body dissatisfaction, and more to do with women's embarrassment in exposing their bodies during examination (i.e. *the necessary intrusion*), which is experienced by many women regardless of body size (Szymonia et al., 2009) and past experiences with healthcare services (Gould, Fitzgerald, Fergs, Clemons, & Baig, 2010; Marlow, Waller, & Wardle, 2015). Therefore, this relationship should be further explored to understand how BMI affects time to help-seeking and the intervening factors that influence and mediate this relationship.

The additional result which identified attendance at regular preventative health screenings as predictive of extending time to help-seeking, challenges reports in the literature suggesting that previous attendance at preventative health screenings shortens time to help-seeking for symptoms (O'Mahony & Hegarty, 2009; Quine & Rubin, 1997). However this reported finding from Chapter 5 may again be understood by negative previous interactions with HCPs during screenings, which influence future healthcare utilisation (Gould, Fitzgerald, Fergs, Clemons, & Baig, 2010; Marlow, Waller, & Wardle, 2015) and may discourage future help-seeking for symptoms. Alternative explanations for understanding this association may be that attendance at regular screening programmes may be presenting a false sense of safety to women (e.g. women may assume that if there was a problem it would be found at the screening), which inadvertently discourages women from seeking help for additional related symptoms experienced between screening appointments, such that women may wait until their next scheduled screening to raise concerns about new symptoms rather than booking an appointment with their GP. Additionally, there may be a lack of knowledge about the specific purpose and limitations of screening tests (i.e. cervical screenings do not screen for or detect *all* gynaecological cancers) (Marlow, Waller, & Wardle, 2015). Without the knowledge of screening, such appointments may not be perceived by patients to be an appropriate setting to raise concerns about symptoms. Nevertheless, such understandings have to the best of our knowledge not yet been reported in current research.

Despite that lack of differences identified across different groups of ethnicity, descriptive analyses highlighted an acculturation variable of 'generations of English speaking in the family', which was associated with 'markedly extended time' to help-seeking of more than one month after detection of PMB. Findings highlight the importance of including acculturation and migration factors in research across ethnicities and cultures, given the limitations of using ethnicity as a descriptive categorisation for various heterogeneous ethnic groupings (Bhopal, 2012; Phillimore, 2012).

Theoretical and Practical Implications

The empirical chapters of this thesis emphasise the important influence of women's environmental context and social milieu on symptom perception, appraisal and the decision to seek help (Burgess, Bish, Hunter, Salkovskis, Michell, Whelehan & Ramirez, 2008; Calnan, 1983; Chatwin & Sanders, 2013; Goodwin, Fairclough, & Poole, 2013; Mwaka et al., 2015; Ramirez, Westcombe, Burgess, Sutton, Littlejohns, & Richards, 1999). Findings suggest that many women choose to confide in family members or a partner (Birt et al., 2014; Scott & Grunfeld, 2009; Whitaker, Macleod, Winstanley, Scott, & Wardle, 2015) and/or self-monitor their symptoms to see whether their symptom improves or worsens. The role of the individual's social milieu and the context in which the symptom(s) occur influence the length of time individuals choose to self-monitor their symptoms (Alonzo, 1984) and ultimately influences time to help-seeking, given that self-management strategies are taken prior to help-seeking and may be a barrier to medical help-seeking (Low, Whitaker, Simon, Sekhon, & Waller, 2015).

Chapter 5 highlighted an additional environmental and social factor that impacts help-seeking, as findings from the multiple regression analyses revealed that individuals who reported high levels of safety within their neighbourhoods sought help sooner than those who reported being affected by a personal experience of crime in their neighbourhood. The association between neighbourhood crime and extended time to help-seeking may be explained by low socio-economic status, lower health literacy (Boxell et al., 2012; Whitaker, Scott, & Wardle, 2015), reduced participation in prevention behaviour, and an increase in risky health behaviours (e.g. tobacco smoking, unhealthy diet, reduced exercise) (Pampel, Krueger, Denney, 2010) when compared with more affluent groups. Therefore, it is important for help-seeking theories to include social-economic and environmental factors, which are likely to impact time to help-seeking.

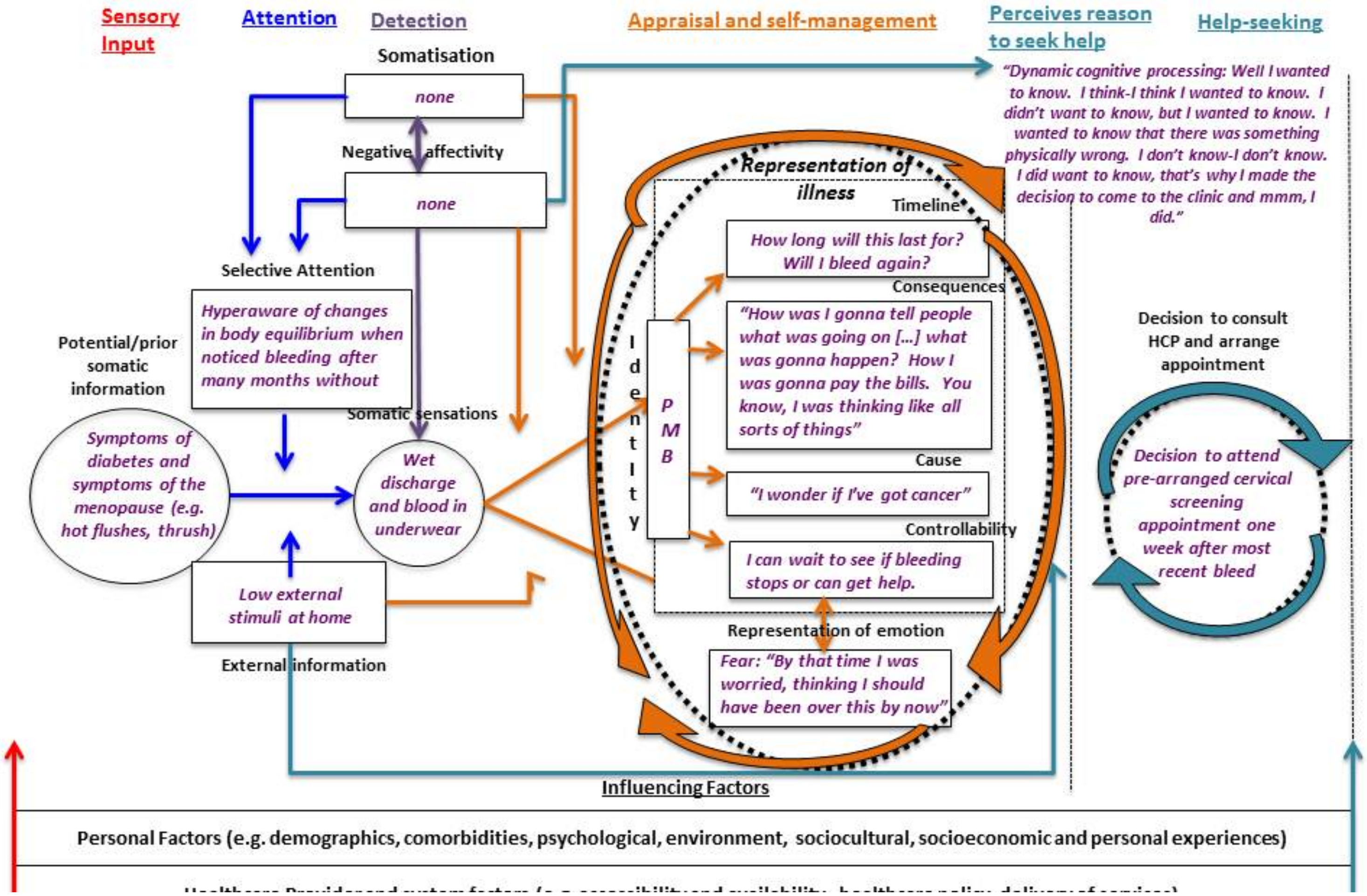
The present research identified additional influencing factors of the HCP (e.g. past negative experiences with HCPs) and healthcare system (e.g. alternative routes to care- not GP), which impacted on participants' utilisation of healthcare services and emphasised the successful alternative routes to care. The Chapter 6 mapping study showed that patients who sought help from emergency services, regular screening appointments or at comorbidity management appointments were all provided with immediate referrals upon their first visit to care. This result was in contrast to some individuals who required more than two visits to their GP (who is the recommended pathway to care; Public Health England, 2015) before receiving a referral to secondary care.

Consequently, sociocultural, economic, personal, and healthcare system factors should be integral into a comprehensive help-seeking model. This suggestion is supported by evidence reported in a recent review by Whitaker, Scott and Wardle (2015) that identified the important impacts of external factors along the many intervals of the help-seeking journey from perception and detection of a symptom to attendance with a HCP. It is therefore important that help-seeking theories include symptom perception processes to build a comprehensive framework from which to gain an understanding of help-seeking for symptoms, given that external factors impact perception processes In response to the previously identified suggestions for a more integrated and comprehensive help-seeking theory, an integrated model was suggested in Chapter 2 that incorporates the key elements of each of the three key models employed in the current thesis and influencing factors that impact these dynamic processes. When combined, these models produce a comprehensive model of help-seeking that encompasses the processes of symptom perception, symptom appraisal, selection and monitoring of coping responses (e.g. self-management) as well as making the decision to seek help from a HCP. Additionally, Figure 8.1, which illustrates the lived experience of a patient according to the integrated model to enable the reader to gain an understanding of this model in action.

Integrated model case example. Figure 8.1 depicts a case example from Chapter 7 of participant Carol (age 53) who experienced a “bit of a bleed” the weekend before her regular cervical screening appointment. Before this time, Carol had experienced slight bleeding on a couple of occasions over the past year, and had recurrent episodes of thrush. However, Carol had not had a menstrual cycle for “about a year”. Her recent experience of vaginal bleeding came as a surprise to her after many months without.

Carol shared her experiences of health and illness with female family members and felt connected with them in a shared experience of diabetes, which ‘runs in the family’ and the menopause. Consequently, she believed that she too should not be bleeding, she “should have been over this by now”. Once the bleeding was discovered she began to ask questions in an attempt to find the answers that could enable her to make sense of her experience. These questions explored the perceived or expected timeline of her bleeding, potential consequences on her family and lifestyle, and the possibility that cancer could be the cause of her bleeding. Her inability to find adequate answers to her questions, the encouragement from her husband and family to seek help, and the fear that her bleeding could be a sign of cancer encouraged her to attend a pre-arranged screening appointment where she intended to report her recent experience of bleeding to a nurse.

In this case example you can see how psychological, biological, and social factors as well as Carol’s personal experiences with previous bleeding played a role in her perception, appraisal of the bleeding as a symptom, and ultimately her decision to seek help for her experience of bleeding. Healthcare system factors also played a role in that her cervical screening appointment, given that her appointment was scheduled prior to her recent experience of bleeding, potentially giving attention to the symptom and increasing the likelihood that she would mention it to the HCP during her visit the following week.



"Dynamic cognitive processing: Well I wanted to know. I think-I think I wanted to know. I didn't want to know, but I wanted to know. I wanted to know that there was something physically wrong. I don't know-I don't know. I did want to know, that's why I made the decision to come to the clinic and mmm, I did."

How long will this last for? Will I bleed again?

"How was I gonna tell people what was going on […] what was gonna happen? How I was gonna pay the bills. You know, I was thinking like all sorts of things"

"I wonder if I've got cancer"

I can wait to see if bleeding stops or can get help.

Fear: "By that time I was worried, thinking I should have been over this by now"

The integrated model acknowledges the dynamic cognitive processes that are involved in the experience of appraising a symptom and coming to the decision to seek medical help and findings from the current empirical studies support the use of model integration in understanding the processes involved in seeking help for a potential symptom of gynaecological cancer. SRM (Leventhal, Brissette, & Leventhal, 2003) provides the framework for an individual to develop representations of their illness and answer the questions in order to gain an understanding of the changes that have occurred in their body. As described in Chapter 7, the decision to seek help was preceded by engagement in a paradoxical cognitive process, characterised by a fear of the unknown, where the decision to seek help was made once the desire to "know" (i.e. what was wrong with one's body) had become stronger than the fear of knowing and the benefits of help-seeking had outweighed the costs. Carol's case provided an excellent example of this dynamic, back-and-forth or circular process when she said, "Well I wanted to know. I think-I think I wanted to know. I didn't want to know, but I wanted to know. I wanted to know that there was something physically wrong. I don't know-I don't know. I did want to know, that's why I made the decision to come to the clinic and mmm, I did."

Furthermore, Chapter 7 highlighted the important role that an individual's social and personal context has on their appraisal of symptom severity. For example, participants' beliefs about when women choose to seek help supported findings from Chapter 4 and previous literature suggesting that individuals are motivated to seek help when they are able to acknowledge a symptom as salient enough to reach a threshold of unmanageability (i.e. *the penny dropping moment)* and in their inability to carry out regular activities of daily life (Macleod et al., 2009; Smith, Pope, & Botha, 2005; Andersen, Cacioppo, & Roberts, 1995). Additionally, women described a cognitive comparing process, which was used in severity appraisal which assessed the quality of their current bleed with past bleeds (e.g. period) and the time since their last menstruation (i.e. pre-menopausal or during the menopause) to subsequently conclude whether they should or shouldn't be bleeding. Therefore, findings illustrated the importance of understanding women's experience of PMB within the context of prior social and personal experiences of menstruation and the menopause. These dynamic and often complex cognitive processes seemingly conflict with the concise clinical guidance provided by clinicians, which suggests that women seek help immediately after they experience vaginal bleeding if it has been twelve months or more after the cessation of their last menstruation (Scottish Intercollegiate Guidelines Network, 2002). This does not fit with the confusing experience that many women have when experiencing the menopause and PMB, given that there are often exceptions to a rule. For example, during the menopausal transition women's menstrual cycles change, often becoming more irregular, and the flow of the bleeding can become lighter, thereby re-defining their previous definition of a menstrual cycle. Additionally, many women may go "about" one year without a bleed or may only notice a minor "show of blood" on the toilet tissue while wiping which may not be acknowledged as a "bleed".

It should further be acknowledged that making the decision to seek help and booking an appointment does not infer help-seeking behaviour and as such, social, personal and healthcare system factors are involved in carrying a decision into action. For Carol, attending her screening appointment did not ensure that she would receive help for her bleeding or even that she would seek help for her bleeding. Carol had to make the choice and remember to inform her HCP of her concerns. Interestingly, Carol did not disclose her bleeding to the HCP until after her examination when she was asked directly by the examining nurse if she had experienced any recent bleeding, and when the last time was that she had a menstrual bleed. The *penny dropping moment* described in Chapter 7 provides insight into theory development, given that it illustrated an immediacy effect or emotional response to the decision to seek help that is partially described by social help-seeking theories such as the Alonzo's (1984) 'containment theory' and Cacioppo and colleagues' (1986) 'threshold of interference' (see Chapter 2). However, the immediacy of the penny dropping moment adds an apparent emotional response that lacks the conscious deliberation into action. Help-seeking literature has identified individuals' affective state, particularly negative affect and fear as influential factors in symptom recognition (Kolk et al., 2003), appraisal (Leventhal, 1970; Pennebaker, 1985) and help-seeking behaviour (Rogers, 1975; Vassend, Skrondal, 1999; Watson & Clark, 1984). However, exploration of the specific roles of emotion in help-seeking is a fairly recent topic for cancer help-seeking research (Balasooriya-Smeekens, Walter, & Scott, 2015). Therefore, findings suggest further investigation to understand the role of emotion to identify key emotions that influence the help-seeking journey (Khakbazan, Taghipour, Roudsari, & Mohammadi, 2014; Kubzansky, DeStano, & Gross, 2013).

Given the complex biopsychosocial influences and the dynamic cognitive processes involved in seeking help for PMB, an integrated model facilitates understanding of the many influences (both known and unknown) on the journey toward help-seeking for potential symptoms of gynaecological cancers. Given that it is grounded in the Model of Pathways to Treatment framework (Scott et al., 2013; Walter et al., 2012), the integrated model may be useful in the investigation of both short and long appraisal intervals with acute and chronic symptoms of illness (Walter et al., 2012), making it suitable for the various symptoms indicative of gynaecological cancers. Furthermore, this model allows for investigation of alternative pathways to care and diagnostic pathways (Walter et al., 2012) that could include seeking help from an emergency department, sexual health walk-in clinic, GP service, regular preventative screening appointment and attendance at a regular comorbidity management appointment (e.g. for diabetes or hypertension). Therefore, in the context of PMB this model could be used to examine help-seeking for PMB, as an acute ("one off show") or chronic (continuous or cyclical bleeding) experience and can further examine the more vague or non-specific symptoms indicative of other gynaecological cancers.

The *practical implications* of the present thesis *and suggestions for changes to practice* suggest that PMB services should provide additional information to menopausal women post-discharge from PMB clinics, and that physicians should be trained to provide supportive communication with patients about the risks of obesity and advice on weight-loss. Therefore, it is important to emphasise supportive as well as practical communication skills in HCP training and practice to ensure positive doctor-patient communication in patient-centred care, which has been shown to encourage future help-seeking behaviours (Amy et al., 2005; Marlow, Waller & Wardle, 2015). Furthermore, given the growing number of obese patients in healthcare services (Bray, dos Santos Silvia, Moller & Weiderpass, 2005; Calle & Kaaks, 2004), GP practices must be able to accommodate women of larger sizes, ensuring the availability of appropriate equipment, and HCPs should receive training to encourage healthy lifestyles amongst their patients as a part of weight and comorbidity management advice. Supportive and accommodating care is likely to encourage future utilisation of healthcare services amongst obese patients.

Psychoeducational and peer support services through the menopause. The women who participated in the patient research made a decision to seek help and engaged in an active search for the answers to explain what was happening in their bodies, what was causing their bleeding and how long it would continue for. During this time most women sought the advice of knowledgeable friends, family members, online sources and HCPs.

Nevertheless, women’s questions remained unanswered and for many women symptoms remained unresolved despite medical help-seeking due to receiving vague or unclear information to reassure them that there was ‘no apparent problem’. Chapter 7 highlighted the need for services to provide post-investigation support for women who are not yet post-menopausal and have been discharged after PMB investigation to wait until they are “fully” through the menopause (i.e. cessation of bleeding after twelve months). This lack of resolve after being discharged from the PMB clinic supports the finding of a study by Tarling and colleagues (2013), which suggested that women may benefit from receiving continued support after discharge from PMB service.

Therefore, the study highlighted a gap in the services, whereby women who are discharged from PMB clinics as a result of not being through the menopause, may benefit from receiving educational information about the common symptoms and possible challenges they may during the menopausal transition. A key symptom of irregular bleeding during the menopause should be highlighted and normalised. Providing statistical information regarding the average estimate or range of time that women may expect this transitional process to last may be helpful to enable women to reduce distress surrounding the bodily changes and may encourage appropriate help-seeking for abnormal symptoms. Furthermore, studies have shown that providing support during and after the menopausal transition can help to reduce distress and improve quality of life and overall wellbeing (Rotem, Kushnir, Levine, & Ehrenfeld, 2006; Toral et al., 2013; Yazdkhasti, Keshavarz, Khoei, Hosseini, Esmaeilzadeh, Pebdani, & Jafarzadeh, 2012). Providing patients with the option to participate in a menopausal peer support group or psychoeducational programme with other women experiencing similar transition difficulties would offer an additional opportunity for women to share their experiences and may help women to normalise their experience rather than feeling that they have to endure their difficulties alone. Such support may encourage future appropriate help-seeking behaviours by facilitating early detection through discussion of bodily changes/sensations (de Nooijer et al., 2001) and continued engagement with health services. Providing access to such groups may also reduce the amount of "trivial" (Hannay, 1979) consultations in primary care services and should further reduce the chance of inappropriate referrals to PMB clinics amongst those who are not yet post-menopausal. Furthermore, providing adequate communication during consultation or communication with other HCPs (e.g. nurses) can provide an opportunity to ask patients how they understand the cause(s) of their symptoms (Petrie & Weinman, 2012).

HCP training and accommodating for diversity. Novel findings of the Chapter 5 study suggested that women who regularly attended preventative health screenings were more likely to delay seeking help. This finding challenges reports in the literature suggesting that previous attendance at preventative health screening appointments shortens time to help-seeking (O'Mahony & Hegarty, 2009; Quine & Rubin, 1997). However, these findings may be explained by negative previous interactions with HCPs during appointments, which influence future healthcare utilisation (Gould, Fitzgerald, Fergs, Clemons, & Baig, 2010; Marlow, Waller, & Wardle, 2015) and may discourage future help-seeking for symptoms. Therefore, it may be necessary to provide communication training to staff, providing techniques that can be used to build trusting and positive doctor-patient relationships, thereby encouraging future help-seeking and ensuring patient-centred care.

The empirical finding of the current research further illustrated a perceived need for HCPs to receive training that would enable them to empathetically address weight concerns in a time-efficient and supportive manner, which would enable the patient and doctor to respectfully discuss weight-related risks and encourage healthy lifestyle changes amongst women. Therefore, despite public health initiatives and clinical guidelines that require HCPs to discuss weight-related issues and assist in weight management programmes (e.g. ‘Every Contact Counts Initiative’; De Normanville, Payne, & Ion, 2011; National Institute for Clinical Excellence [NICE] guidelines, 2014; Royal College of General Practitioners, 2014), this study supports findings from previous literature, which suggests that HCPs continue to describe weight-related discussions with patients as challenging and uncomfortable (Jackson et al., 2013). Findings of Chapter 7 further suggested novel finding in help-seeking research, which suggested a lack of knowledge about the benefits of weight-loss (i.e. how it can help) in improving health and wellbeing and reducing the risk of developing some cancers amongst obese women, particularly endometrial cancer. This is important because, training may further increase clinicians’ self-efficacy and comfort in discussing weight-related risks and supporting weight-loss whilst maintaining a positive doctor-patient relationship. Although weight-loss plans are most suited to primary care services, all HCPs in both primary and secondary care services should receive effective communication training. Furthermore, despite women’s expressed preference for a female doctor over a male (in Chapter 7), Gray (1982) reported that patients believed the ability of a doctor to relate to patients on a personal level was more important than their gender, and this included taking a personal interest in the patient, explaining things in detail and taking the time to be with their patients. A study by Maguire and Pitceathly (2002) showed that clinicians who lack proper communication training are experienced by patients as lacking the empathy necessary to provide patient-centred care. Therefore, it is important for these skills to be emphasised in GP training and for practice to foster positive doctor-patient communication that encourages future help-seeking behaviours (Amy et al., 2005; Marlow, Waller, & Wardle, 2015), which may reduce gender-specific doctor requests that have the potential to cause system delays due to limited staff availability.

Additionally, GP practices must be able to accommodate women of larger sizes, ensuring the availability of appropriate equipment and HCPs should receive training to encourage healthy lifestyles amongst their patients. Supportive and accommodating care is likely to encourage future utilisation of healthcare services amongst obese patients. In view of thesis findings, which suggest a limited awareness of gynaecological cancers, particularly regarding the risk of obesity and the development of gynaecological cancers, weight-loss advice should be directed toward improvement of health and reduction of risk for common obesity-related diseases and cancer.

Therefore, the current thesis research emphasised the important role that the healthcare system practices, patient support services, doctor-patient communication, and availability of appropriate equipment has on patient help-seeking for gynaecological cancers. These factors have not been suggested together in previous research on help-seeking in the context of gynaecological cancer symptoms.

Gynaecological awareness research and intervention. Findings of the thesis are consistent with those reported in the literature suggesting that women have a low awareness of the symptoms indicative of gynaecological cancers (Boxell et al., 2012; Cooper, Purvis, Polonex, Stewart, & Gelb, 2013; Sheikh & Ogden, 1998; Jayde, White & Blomfield, 2010) and only 13% were able to identify their symptom of PMB as a warning sign of cancer. However, the conclusions cannot be drawn from the current study regarding the relationship between knowledge of PMB and time to help-seeking for PMB as a symptom, given that this was not specifically addressed in the gynaecological awareness of symptoms measure and was referred to as “abnormal bleeding”. Nevertheless, due to the complexity of the referrals –

(which included women who were not post-menopausal) this omission does not affect the results of the study and was in line with the aim of the study to identify awareness of common symptoms of gynaecological cancers in general. Future research should measure time to help-seeking according to identified symptoms to assess for differences in awareness and time to help-seeking across specific symptoms of gynaecological cancers. Few studies have been reported to test knowledge of gynaecological risk factors, particularly the risk factor of obesity on the development of gynaecological cancers (Soliman et al., 2008). Thus, future research should investigate the awareness of risk factor knowledge amongst a larger sample across the UK. Nevertheless, as noted in Chapter 2 and demonstrated in the results of Chapter 5, knowledge alone does not predict help-seeking behaviour (Murray & McMillan, 1993; Scott, 2010; Sheikh & Ogden, 1998) and further efforts should be made to encourage women to seek help for symptoms *as well as* attend preventative screenings.

The Chapter 5 study revealed no differences in symptom or risk factor knowledge for gynaecological cancers across ethnicities and no relationship was found between gynaecological cancer awareness and time to help-seeking, suggesting that awareness of symptoms and risk factors for gynaecological cancers did not differ between women who delayed seeking help and those who did not. However, most of the participants in the study had low to moderate scores of gynaecological awareness, hence the relationship between awareness and time to help-seeking may have been stronger for more extreme scores in awareness. Nevertheless, this finding raises a question regarding the effectiveness of awareness-based interventions on decreasing time to help-seeking. Although, it should be acknowledged that due to the non-validated nature of this measure and the general overview of gynaecological symptoms and risks, the measure may not have related specifically to PMB and therefore may not reflect awareness for PMB specific risks and the associated symptom(s).

Knowledge of obesity as a risk factor is mixed across the studies, suggesting that more than half of the women in the study were not able to acknowledge obesity as a risk factor for the development of gynaecological cancers. Yet one third did not identify it as a risk (see Chapter 5). Qualitative results of the Chapter 7 interview study revealed that although most women were knowledgeable about the risks that obesity posed on their general health, they did not show an awareness of the increased risk associated with cancer (Soliman et al., 2008), nor were they able to describe *how* obesity increases risk for disease.

The thesis highlighted not only a lack of knowledge of the risks of obesity and disease, but also an additional lack of knowledge about the benefits of weight-loss (i.e. how it can help) in improving health and wellbeing and reducing the risk of developing some cancers, particularly endometrial cancer. This was depicted in the Chapter 7 IPA study wherein the 'catch-22' described a conflict between the dichotomous decision to choose to treat comorbid conditions (e.g. diabetes, hypertension, arthritis) over weight-loss, which suggests contradictory definitions of health and weight-loss that do not acknowledge the association between obesity and the development of comorbid diseases (Must, Spadano, Coakley, Field, Colditz, & Dieta, 1999). Nevertheless, despite women's lack of knowledge about the risk factors of obesity and cancers (Soliman et al., 2008), and an expressed low body esteem or 'hatred' for their weight, women did not believe that their larger body size or personal body image played a role in their help-seeking experience or time to help-seeking, which supports findings from Chapter 5 suggesting that knowledge of gynaecological cancers was not different across participants who extended their time to help-seeking and those who did not. Therefore the findings of the thesis studies revealed a lack of awareness of obesity as a risk factor, which may be connected with how they feel about their own weight,the benefits of weight-loss on health and their beliefs about their abilities to lose weight.

Given the limited general awareness about gynaecological cancers amongst women, intervention should be developed to improve public awareness of gynaecological cancers. Current initiatives, interventions and awareness campaigns in the UK are run by the Cancer Research UK, which currently leads the National Awareness and Early Diagnosis Initiative and aims to improve awareness of the signs and symptoms of cancer amongst the public, encourage those who are experiencing symptoms to seek help earlier than is currently reported, and to support primary care in diagnosing cancer earlier. These aims support diagnosis at earlier stages leading to improved patient outcomes for common cancers (Department of Health, 2011). This initiative suggests that earlier presentation to primary care for people experiencing potential symptoms of cancer can be achieved through a public change in behaviour toward help-seeking. Government driven campaigns have been running since 2010 (Department of Health, 2011; 2014) and evidence has shown effectiveness of interventions) to improve symptom awareness and encourage presentations at primary care by reducing barriers to help-seeking for various cancer types (Austoker et al., 2009; Department of Health, 2014). However, for gynaecological cancer much of the campaigns have focused on prevention strategies and encouraging regular attendance at cervical screenings, expanding screening programmes to include ovarian cancer screening (CA125 blood test; UK Collaborative Trial of Ovarian Cancer Screening) and encouraging young women to receive an HPV vaccination from primary care (Department of Health, 2014).

A systematic review of research conducted in awareness and early presentation for many different cancers (Austoker et al., 2009) reported that interventions targeted to individuals may increase cancer awareness, for example by receiving a information and/or a pamphlet from a healthcare professional was most affective. Alternatively, interventions delivered to communities (e.g. media campaigns, information available in public space) were suggested to promote both cancer awareness and early presentation, although there was limited evidence across studies to support this. In a study by (Robb et al, 2009), awareness of many cancer warning signs were low particularly for those from lower socio-economic status (SES) or ethnic groups. Some common barriers to help-seeking included difficulty booking an appointment, concerns that one was wasting the doctor's time and concern about the outcome of the investigation. The report suggested that interventions should combine public education (i.e. symptom awareness) with encouragement for people to seek medical advice, along with further support at the primary care level. These suggestions were posited to improve early presentation and cancer outcomes.

Local and national intervention campaigns that work in partnership with primary care services have been developed to encourage disadvantaged communities and different ethnic groups to seek help promptly for symptoms and to raise awareness of cancer symptoms (Department of Health 2011; 2014). However, there remains a need for culturally sensitive, community-based interventions to raise awareness and encourage early presentation (Waller et al, 2009). Common methodologies being used to raise awareness and encourage prompt help-seeking for various cancer symptoms include social marketing campaigns to promote the early signs and symptoms and the development of local campaigns that bring together healthcare professionals, charity organisations and the general public to raise awareness and provide accessible information to the public, particularly to those most at risk (e.g. smokers) Department of Health, 2011).

A study by Evans et al., 2014 interviewed GPs to understand their attitudes toward a public gynaecological awareness campaigns and addressed their views about the potential impact of increased awareness on primary care services, resulting in increased burdens Results of this study identified that GPs believed awareness interventions in the community would improve patient's awareness of gynaecological cancers and would encourage timely help-seeking, however they expressed concerns about a resulting increase in rates of presentation and costs on primary care resources (e.g. additional consultations, investigations and referrals). Therefore this study suggested that further research be undertaken to compare the benefits of earlier diagnosis in gynaecological cancers against costs on resources.

Further research into gynaecological cancer interventions has revealed mixed evidence in the effectiveness of community-based awareness campaigns, with the most being distributed via advertisement and TV to increase awareness of gynaecological cancer symptoms campaigns. Such campaigns aim to minimise time to help-seeking or rates of gynaecological cancer diagnoses, however evidence suggests an increase in the number of gynaecological urgent GP referrals (Department of Health, 2014). Women under the age of 50 represent the largest increase in referrals (35%), with women between the ages of 70 and 79 showing the smallest increase (14%) (Department of Health, 2014). Therefore, previous research highlights that caution should be taken when identifying appropriate methods for intervention when the aim is to raise awareness and encourage early presentation of gynaecological cancer symptoms, such that it should avoid placing undue cost on healthcare resources, including providing unnecessary referrals for symptoms not indicative of gynaecological cancers.

Nevertheless, given the results of this thesis research, women have shown a low awareness of not only the symptoms, but also the risk factors that may lead to the development of gynaecological cancers. Therefore, intervention to improve awareness of these two key factors may be important in influencing early detection and diagnosis.

Given that previous research has highlighted the important role of sociodemographic factors on disease awareness, intervention should follow a theoretical framework to identify patients' illness beliefs, threat appraisals and affective states while acknowledging the sociodemographic factors that affect disease awareness (Boxell et al., 2012). To improve cancer awareness, Whitaker et al. (2015) posit that health literacy is a key component in effective public awareness campaigns and interventions, such that lower literacy may make public health messages more difficult to comprehend (Doak, Doak & Meade, 1996) and may account for socio-economic and cultural disease disparities. Therefore, it is important for interventions to target high-risk populations and encourage women to pay attention to their bodily sensations, to provide education to the public that would enable women to accurately appraise their symptom as warning sign of cancer, and to enable women to better understand their own personal risk for disease (Whitaker, Scott, & Wardle, 2015). Additionally, women should be positively encouraged to seek help from supportive and knowledgeable HCPs while educating women on the importance of early presentation on less invasive treatment and improved survival outcomes.

When targeting populations for interventions and prevention campaigns it is important that interventions access the public as a whole and not merely women engaged with healthcare services. This is important, given the influence of social networks on help-seeking behaviour (Burgess et al., 2008; Low et al., 2015; Whitaker, Scott, & Wardle, 2015) described earlier in this chapter. Screening programmes should be further aware of what information is provided about screening services and prevention programmes, such that there should be a clear understanding about the purpose and limitations of cervical screenings (i.e. what it can and can't do) (Marlow, Waller, & Wardle, 2015). Additionally, services should be cautious about presenting a false sense of safety to women attending regular screenings that may influence future help-seeking when women develop potential symptoms of gynaecological cancer (between regular screening appointments). Public health awareness campaigns should address the role of preventative screenings as a means of identifying cervical abnormalities to detect issues not yet known to the patient and to encourage women not to use screenings as a substitute for seeking help for additional symptoms (although detection of other cancers can sometimes be an outcome of examination during screenings). Furthermore, given the number of women who choose to self-monitor before seeking help, it may be useful for public health campaigns to share common self-management strategies employed by women with gynaecological cancer symptoms with the public to build a conscious awareness of self-management behaviours so that they may be more readily able to identify their own behaviours when they engage in self-management behaviours as a substitute for medical help-seeking. Information should address the context of the symptom(s) relevant to the at risk groups. For example, the symptom of PMB should be placed in the context of experiencing a significant change during the midlife and completion of the menopausal transition (i.e. twelve or more months break between bleeds), to distinguish PMB from irregular bleeding during the menopause.

Clear and concise information can be distributed and made available in public settings throughout the community (e.g. supermarkets, bus stops, buses, television media) and not merely within primary care services. However, where relevant, interventions individual interventions by healthcare professionals should be implemented in primary care (e.g. giving patient a pamphlet and/or explaining associated disease risks such as obesity). Furthermore, information should be made available to individuals from diverse cultural and ethnic groups (Marlow, Waller, & Wardle, 2015) by providing information in various different languages and allowing access to information for individuals who may be unable to read or write.

Limitations and Future Directions*Limitations.* The key limitations of the thesis include (a) methodological issues (i.e. the self-report and retrospective methodology of the patient help-seeking studies, timing of the study in patients), (b) the inclusion of people who sought help via cervical screening and not at presentation at GP surgeries, and (c) the sample size, which may not have had sufficient power given the cross-validation sample, (d) recruitment limitations and questionnaire complexity, and (e) the categorisation of ethnicities into groups.

An unexpected lack of association was found between many of the variables in the journey to help-seeking studies, which may be due to methodological choices made regarding retrospective self-report questionnaires and estimation of dates which were used to measure outcome variable for time to help-seeking, rather than *actual* dates of presentation at GP services. The objectivity of the outcome measure may be challenged given that they were obtained from self-report estimation dates that were rounded up or down respectively by two weeks, making approximation dates for the beginning, middle and end of the month. These general date estimates may have influenced the findings of Chapter 5 by incorrectly placing a participant into an extended time to help-seeking category, due to an incorrect estimate, or in Chapter 7 by missing relationships that may have existed between obesity and time to help-seeking or ethnicities and time to help-seeking, given that time intervals of the patient journey were measured in days Therefore, a more objective measure would have been necessary to obtain exact dates from GP record systems or to round to the nearest one or two weeks for *all* participants and map the journey to help-seeking accordingly (by one or two week intervals, rather than using number of days). Nevertheless, these issues are common challenges in help-seeking research. Much of the research in the field of help-seeking employ retrospective data collection methods (Scott & Walter, 2010), and for those who acquire data from GP record systems, not all GP surgeries adequately document patients' experience of symptoms (Kroenke, 2001). Alternatively a calendar method may be suggested for use in help-seeking research, which can aid participant recall by acknowledging crucial events that occurred along the journey to help-seeking (van der Vaart, 2004).

Furthermore, in terms of the self-report methodology, accurate recall of the length of time taken for women to become concerned about a symptom or to contact healthcare services may have been difficult. To overcome this limitation, data in the form of date of first contact and number of contacts made with the PMB clinic prior to the most recent visit should have been collected, given that previous visits to the PMB clinic fast-tracks the pathway to investigation and diagnosis. This may have provided a more objective measure of time to contacting or visiting healthcare services and would have allowed the number of prior visits to be measured as a factor that may have influenced time to help-seeking.

Although much of the help-seeking research is conducted retrospectively, Andersen et al. (1995) suggested that help-seeking behaviour should be examined through longitudinal or even experimental designs (Andersen, 1995). Experimental designs could be used to identify influencing factors on symptom perception, appraisal and intention to seek help and to pilot interventions (Scott & Walter, 2010). In the current study another option would have been to conduct a longitudinal prospective study tofollow women from the moment they contacted their GP to the moment they were seen at the PMB clinic, given that aiming to contacting women at the moment they detect PMB would is not feasible.

Additionally, women who attended the PMB clinic via attending a cervical screening rather than seeking help for a symptom may have affected the findings given that they did not report a concern prior to seeking help, which was developed under the assumption that 'time of concern' would be the first phase of the help-seeking journey, raising questions about the definition of the interval 'recognising a bodily change'.

Limitations may exist with the sample size, such that the sample size may not hold sufficient power for the cross-validation sample, and may have identified stronger relationships between variables if there were more participants in the predictor study. Therefore, there may have been variables that were not acknowledged by the multiple regression analysis, due to the subtle relationships and small sample size. Nevertheless, for the scope of the thesis research the sample size was deemed appropriate according to power calculations prior to the cross validation analysis. An important limitation of the questionnaire study involved the complex and lengthy nature of the questionnaire, which may be responsible for the incomplete questionnaires returned to the researcher. A more hands-on approach to researcher-guided questionnaire completion may have increased the numbers of fully completed questionnaires. In this approach, the researcher would go through the questionnaire with each participant, and those who decide to take the questionnaire home could receive a follow-up phone call to aid with completion of the questionnaire. Furthermore, phone calls should have been made to participants to complete missing sections in mailed questionnaires returned to the researcher (S. T.). However, phone numbers were not provided by participants at the time of consent. An additional limitation of the Chapter 5 study was present in the data collection design which involved various times of questionnaire completion amongst participants which may have affected participant responses (i.e. in clinic *prior* to seeing the consultant at PMB service and at home *after* seeing the consultant for PMB).

Finally, the collapsing of ethnicities into the BME grouping encompasses a variety of cultures, races and religions that exist in the Birmingham and West Midlands region (Office for National Statistics, 2012), which are not distinguished or defined separately in the current study. Readers must therefore be cautious when interpreting and generalising findings to wider cultural contexts. Grouping ethnic minorities into one generalisable group can be problematic given that the UK's ethnic diversity changes geographically throughout the nation. Furthermore the term ethnicity can include additional perceptions of cultural, socio-economic, socio-political and genealogical understandings into the definition (Vickers, Craig & Atkin, 2012), and grouping Black, Asian and minority ethnic groups together does not assume homogeneity across these groups.

Predicting help-seeking for gynaecological cancer symptoms. Future research will be necessary to: (a) better understand the relationship between BMI and time to help-seeking as well as the intervening factors that influence this relationship for women experiencing potential symptoms of gynaecological cancers (as described above), (b) to clinically define 'immediate' help-seeking for PMB symptoms described in the literature (Center for Disease Control and Prevention, 2014; NICE, 2005; Pan Birmingham Cancer Network, 2015), and (c) to understand the role of sociocultural and economic factors on symptom appraisal and the decision to seek medical help, as well as to identify disparities in time to help-seeking across groups. Furthermore, research should be conducted to explore the integrated model of help-seeking in the context of gynaecological cancers.

Future research is needed to identify the relationship between BMI and help-seeking for gynaecological cancers, suggesting that future research should employ a design with a stratified sample to account for a curvilinear relationship and the complexities of understanding the relationship between obesity and medical help-seeking.

Nevertheless, in order to ensure that the findings of this thesis clinically are relevant and to prioritise research in the area, it is important to gain an understanding of the clinical importance of prompt help-seeking and the effect of extending time to help-seeking for symptoms of PMB on survival outcomes. Thus, future research should identify clinical evidence for the use of 'extended time to help-seeking' (i.e. delay) defined cut-off points for PMB using the outcome measure employed in the current thesis (i.e. two or more weeks after detection) to identify the potential for increased risk of malignancy after a determined number of days from PMB detection.

The present research supports the literature which suggests that socio-economic factors play a key role in extending time to help-seeking for symptoms of cancer (Low et al., 2013a; National Cancer Intelligence Network, 2009a), and are associated with reduced cancer awareness (Boxell et al., 2012; Power, Simon, Judzczyk, Hiom & Wardle, 2011; Robb et al., 2009). Low and colleagues (2013a) posit that this disparity might be due to referral delay from GP surgeries to secondary care, however, findings of the present research do not support this claim, as results do not identify differences in referrals between White European and BME groups or across levels of deprivation. Alternatively, according to Whitaker, Scott and Wardle (2015) lower awareness of symptoms, including poor health literacy, may influence misinterpretation of symptoms, hence extending appraisal time amongst patients of low socio-economic status. This may explain the late-stage diagnosis reported for ethnic minority and low socio-economic groups (National Cancer Intelligence Network, 2009a, 2009b). Furthermore, despite the minimal differences found across groups of ethnicity, findings appear to suggest that social (i.e. neighbourhood crime) and acculturation factors (i.e. generations of English speaking in the family) might be associated with an extended delay to help-seeking. Therefore, the thesis proposes that future research should investigate sociodemographic factors, health literacy, social capital and disease awareness amongst patients seeking help for gynaecological symptoms, and assess for possible disparities of help-seeking across socio-economic groups, ethnicities and obese women, given their increased risks of developing gynaecological cancers.

Given that socio-demographic factors influence symptom perception, appraisal, self-management behaviours, help-seeking behaviour, health literacy and disease awareness, it is important that research examines the factors that interact with the processes of help-seeking for cancer symptoms, to form a better understanding of the socio-demographic factors that influence symptom interpretation and decisions to seek help (Whitaker et al., 2015). Such research should be used to inform intervention development and improve cancer disparities across different sociocultural and economic groups (Madison, Schottenfeld, James, Schwartz, & Gruber, 2004; National Cancer Intelligence Network, 2014). Additionally, research should continue to explore help-seeking from alternative routes to care (Ellis-Brookes et al., 2012) for gynaecological cancer symptoms (e.g. Emergency services, GP, other) and across levels of obesity, socio-economic status and ethnic minority groups with gynaecological cancer symptoms.

In acknowledging the lack of comorbidity reporting in the present research and the association between comorbid diseases and gynaecological cancers (e.g. diabetes & hypertension), future studies should report the type of comorbid diseases (with medical diagnoses) present amongst participants in the sample to assess for the association between comorbidities, comorbidity management services, and time to help-seeking. Barsky and colleagues (2001) suggest that pre-existing comorbidities have an important potential to bias both attention to bodily sensation(s) and the appraisal of symptoms, thus impacting an individual's method of help-seeking.

Given the mixed and novel findings derived from the present research, a wider multi-site study should be conducted across the UK to assess the relationship between BMI and help-seeking and the impact of negative past experiences in help-seeking, attendance at preventative healthcare screenings and help-seeking for the various vague and non-specific symptoms of gynaecological cancers.

Conclusion

Results of the research advanced our knowledge and understanding of help-seeking behaviour for symptoms of PMB and the differences that exist between obese women and non-obese women in time to help-seeking, as well as the experience of utilising gynaecological healthcare services. Moreover, findings challenged previous assumptions in the literature which suggest that obesity acts as a barrier to medical help-seeking and that previous attendance at preventative health screenings shortens this time. The present research showed that obese women were *not* more likely to delay help-seeking when compared to non-obese women, that attendance at preventative screenings *was* a predictor of delayed help-seeking, and low awareness of gynaecological cancers was *not* associated with delay. Finally, this thesis provides an understanding of the often complex transition through the menopause and women's experiences with making sense of a potential symptom of gynaecological cancers.

This thesis suggests the need for healthcare services to adapt their practice to meet the specific needs of obese patients, highlighting potential misconceptions amongst HCPs that obese women are more likely to delay help-seeking. Furthermore, despite the minimal differences found across groups of ethnicity, findings appear to suggest that social and acculturation factors might be associated with an extended delay to help-seeking and should therefore be further explored in future research. In view of the increasing evidence that obesity is a risk factor for the development of gynaecological cancers and the reduction of survival rates, a large multicentre study should be conducted to confirm the findings amongst

PMB as well as the more vague and non-specific symptoms common of gynaecological cancers.

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APPENDIX A

Chapter 4: Ethical Approval Letters

APPENDIX B

Chapter 4: Consent form for Participants

UNIVERSITY OF
BIRMINGHAM

Understanding the perspective of the healthcare professional in help-seeking among obese women experiencing symptoms of gynaecological cancer

Consent Form for Participants

Please initial each statement to indicate agreement.

☐ I have read and understood the information sheet for the above study and have been given the opportunity to ask questions.

☐ I understand that my participation is voluntary and that I am free to withdraw from the study up until __(JANUARY, 2015)___without having to give any reason and without me being affected or this having any negative consequences on my circumstances.

☐ I agree to provide information that will be used for research purposes only, and understand that all the information relating to myself obtained as part of the study will be strictly confidential, and that I will not be personally identified in any write-up of the results.

☐ I understand that information will be stored in secured manual and electronic files and is subject to the provisions of the Data Protection Act.

☐ I consent to being audio and video taped for the purpose of transcription and data collection in this focus group discussion.

☐ I wish to participate in this study under the conditions set out here and in the Information Sheet for Participants.

Signed: ____

Printed Name: _______________________________________

Date: _________________________

APPENDIX C

Chapter 4: Information Sheet for Participants

UNIVERSITY OF BIRMINGHAM

Information Sheet for Participants

Study Title: Understanding the perspective of the healthcare professional in help-seeking among obese women experiencing symptoms of gynaecological cancer.

Introduction:
You are being invited to take part in the present study. Please take the time to read through the following information. Ask the relevant person who provided you with the information sheet if you have any questions or would like more information.

What is the purpose of the study?
The purpose of the present study is to hear about your experiences with obese women presenting with symptoms of gynaecological cancers in your healthcare service. We are interested to hear what you think and believe may contribute to patient delay in help-seeking for symptoms of gynaecological cancer. We are also interested in learning more about your general beliefs and interpretations about the experience of obesity in women who present with symptoms of gynaecological cancers. We are also interested in hearing any suggestions you have which may help encourage or facilitate early help-seeking among obese women. The study will also provide a knowledge base from which to develop future research on the investigation of barriers to help-seeking from the patient perspective and will inform the development of interventions to challenge obese women's beliefs about the symptoms and risk factors for gynaecological cancer and improve help-seeking.

The study is in the form of an interview between you and the principal researcher. It will last 30-40 mins and will be audio-recorded to ensure clarity of data collection and transcription.

Why have I been chosen?
You have been chosen to participate in this study because you have been identified by representatives of your field as having experience working in direct care with the population of interest (obese women presenting symptoms of gynaecological cancer).

Do I have to take part? / What happens if I take part?
It is entirely up to you whether you decide to take part in the present study or not. If you decide to take part, you will be given this information sheet to keep and a meeting in the form of an interview will be arranged for you, which you will be asked to attend. Even if you decide to take part, you are still free to withdraw from the study at any time up until **a month post completion of the interview**, without having to give any reason. Withdrawing from the study will not affect you or have any negative consequences on your circumstances.

You will have an option of participating in the interview face-to-face at your place of work, at the University of Birmingham Psychology Department, via phone, or Skype.

What happens to my information?
All information that is obtained from the interview will be uploaded onto a password protected computer for use of transcribing. Only the transcriber and research team will have access to these materials. This information will then be entered into a computer database, where your information will be assigned a number. The information in the database, as well as all study material (i.e., audio files), will be identified by numbers, and can therefore not be traced back to you or anyone else. Once the audio files are transcribed all digital copied and original files will be deleted. Your name will only appear on your consent form, and the researcher will be the only person who

has access to a list linking your name with your number. All study material, including audio records of interviews, will be kept in a locked filing cabinet at the University of Birmingham.

Will my taking part in this study be kept confidential?
All information that is obtained during the course of the study will be kept strictly confidential. No identifiable information will be included in any publication using the data of this study.

What will happen to the results of the study?
The results of the study will be analysed by the research team to identify the experiences of healthcare professionals working with obese women presenting symptoms of gynaecological cancer. The results may be presented at a conference or published in an academic journal and may be used to inform future research regarding the experience of obese women with symptoms of gynaecological cancer Please note that no identifiable information will be released in any write-up of the results. If you choose to participate in the study and would like to receive a copy of the results or final paper you may state this at the start of the interview and a copy of the results will be sent to you via the contact information you provide.

Please contact Sara Tookey with any questions you may have.

If you are interested in participating in this study and have not yet indicated your time preference, please contact Sara Tookey and include:

- Preferred dates and times which are most convenient for you to complete the interview
- Location and mode of interview you prefer (face-to-face at your work or the University, via phone or Skype)

Sara Tookey
PhD Researcher
School of Psychology
University of Birmingham
Edgbaston, Birmingham
B15 2TT

Dr. Beth Grunfeld
Senior Lecturer and Research Supervisor
School of Psychology
University of Birmingham
Edgbaston, Birmingham
B15 2TT

APPENDIX D

Chapter 4: Interview Schedule

1. Exploring Context

Could you please tell me a bit about your place of work?

What's your professional role? What kind of patients do you see? What does your office look like?

What percentage of your patients would you say are obese or overweight?
In what capacity would do you work with them?

2. Narrowing in on the Patient Process of Coming into Care

What is the process for a patient to be able to seek your services?

Do they have to be referred?
What does screening entail?
What is involved in seeking help for symptoms of gynaecological cancer?

What is the screening process like for obese women?
Are there difficulties for them/ you?
Do you regularly make adaptations to aid in the process for them? (i.e. larger equipment, extra time to conduct screening, larger gowns)
What are their attitudes toward vaginal examination?
Do you always have equipment available for obese patients? What if it wasn't?

What is the patient process of obese women seeking help?
Does it differ from non-obese patients in any way?
What do you believe are the attitudes obese women hold toward seeking help for any health related symptom?
What do you believe to be the barriers for seeking help amongst obese women?

3. Patient and the Healthcare Professional: The Experience

What do you think women know about the symptoms and risk factors for gynaecological cancer?
Have you noticed any different beliefs amongst this group?
What are the motivators to seek help for them?
What get's in the way of these women seeking help?
Does this differ by ethnicity/ race/ culture?

What is it like working with this population?
What's it like to treat them?
Are their challenges or difficulties in working with the obese female population within your services?
As part of your role do you advise patients to lose weight? (at what stage in treatment was this?) What is that like?

What do you think it would be like to be an obese female service user?
What would you notice about your care, the equipment, or your service care providers?

4. Suggestions for improving help-seeking

And finally, do you have any suggestions on how to improve help seeking in obese women with symptoms of gynaecological symptoms?
Suggested interventions?
Changes to the clinic, practice, doctor-patient relationship, referral process, resources, equipment.

APPENDIX E

Chapter 5: Definition of Questionnaire Variables

Definition of Variables

Variables	**Method of Data-collection**	**Description**	**Inclusion in Analysis**
Sociocultural & Demographic Variables			
Age	Self-measured	Subtraction of date of birth from date on the consent form.	√
Marital Status	Self-measured	Indicated using a categorical variable, including five status designations.	√
Employment	Self-measured	Indicated using a categorical scale, including five status designations.	√
Personal Deprivation Index	Self-measured	Assessed availability of material resources to an individual. Indicated by agreement to the following statements (each scored as 1 with maximum score total of 5): No central heating in household; No telephone in household; No car available; Do not own home; Receive income support/benefit.	√
Education Level	Self-measured	Highest level of education completed using a categorical scale ranging from a value of one, indicating Less than compulsory education according to UK education standards to a value of 4 for further postgraduate education.	√
Years of residence	Self-measured	Subtraction of date arrived in the UK to the date on consent form.	√
Country of origin	Self-measured	Open-ended response.	√
Religion	Self-measured	Indicated using a categorical scale of 6 possible responses and 2 additional items of ‘none’ and ‘other’.	√
Language	Self-measured	Indicated using a categorical scale of 18 possible items and an open-ended option of ‘other’.	√
Ethnicity	Self-measured	Indicated using a categorical scale of 17 possible items and an open-ended option of ‘other’.	√
Generations of English language	Self-measured	Indicated by ordinal scale of English speaking in family: Self (=1), Parents (=2), Grandparents (=3) & Great-grandparents (=4). If ‘none’ is indicated the participant did not speak English.	√
Objective body size/weight & Body image			
Body Mass Index	Measured by nurse in clinic	BMI = x KG / y M(^{2}).; Categories of obesity defined by WHO, 2000.	√
	Underweight	Individuals measured at BMI <18.5.	√

Normal weight		Individuals measured at BMI 18.5-24.9.	√
Overweight		Individuals measured at BMI 24-29.9.	√
Obese		Individuals measured at BMI 30-39.9 with a waist circumference >88cm.	√
Morbidly obese		Individuals measured at BMI >40 with a waist circumference >88cm.	√
Waist-to-Hip Ratio	Self-measured	Measure of cardiovascular health. To determine the ratio, waist measurement is divided by hip measurement. Detailed instructions for measurement provided to participant with a tape measure. Measures of over .8 indicate poor cardiovascular health.	√
Body Image	Self-measured	Sixteen item questionnaire to assess for concerns with one's body shape (BSQ-16A) (Evans & Dolan, 1993).	√
Mood			
Anxiety and Depression Scale	Self-measured	The Hospital Anxiety and Depression Scale (HADS) (Zigmund & Snaith, 1983). Assesses mood using the 14 item scale assessing for mood in the past week scoring participants into ranges of anxiety and depression; (0-7, normal), (8-10, moderate) and (16-21, severe).	√
Illness Perceptions			
Illness Perceptions Questionnaire-Revised	Self-measured	The Revised-Illness Perceptions Questionnaire (IPQ-R) (Moss-Morris et al., 2002; Weinman, Petrie, Sharpe, & Walker, 2000) was adapted to assess PMB and gynaecological cancer specific beliefs. Scales include Identity, Timeline, Consequences, Cause, and Control of the participants; current condition. Wording and terms were changed to include symptoms of gynaecological cancers and the word illness was changed to 'condition', as participants are pre-diagnosis and an assumption of future diagnosis could increase anxiety.	√
Identity		Identity of a participant's condition measures using a symptom identification scale requiring participants identify if they experienced any of the listed symptoms.	EXCLUDED
Timeline (Acute/Chronic)		Items of the subscale measure length of time they believe their condition and/symptoms will last from acute (short time) to chronic (long time). Assessed by 6 statements requiring identification of level of agreement.	√
Timeline (Cyclical)		Items of the subscale measure if participant believes the symptoms are cyclical nature. Assessed by 4 statements requiring identification of level of agreement.	√
Consequences		Items of the subscale measure the perceived consequences of the condition on one's personal and social life. Assessed by 6 statements requiring identification of level of agreement.	√

Control		Items of the subscale measure perceived amount of control one has over their condition, effectiveness of treatment and treatment control and the effectiveness of prevention and ability to prevent future diagnosis. Assessed by 11 statements requiring identification of level of agreement.	√
Illness Coherence		Items of the subscale measure participants' understanding and possible confusion related to their condition. Assessed by 5 statements requiring identification of level of agreement.	√
Emotional Representations		Items of the subscale measure associated emotional responses of fear, anxiety, anger, depressed mood and general upset. Assessed by 5 statements requiring identification of level of agreement.	√
Gynaecological cancer awareness			
Knowledge of risk factors & Knowledge of symptoms	Self-measured	Gynaecological cancer awareness is assessed using 2 tests where a participant must indicate identify risk factors and symptoms of gynaecological cancers from a list of possible risk factors and symptoms. Knowledge of symptoms included 17 items and knowledge of risk factors was 20 items.	√
Social influences			
Social Capital	Self-measured	Social capital is defined as the degree of social cohesion with social networks, familial relationships and reciprocal trust within a community, which constitutes social belonging and civic identity (Morrow, 1999). The measure was derived from National Centre for Social Research and University College London (2011) and Gootaert, Narayan, Jones & Woolcock (2004) shortened version.	INCLUDED SUB-SCALES
Past health behaviours			
Health History	Self-measured	A twelve item scale requiring identification of level of agreement on statements relating health history practices (i.e. regular participation in screening programmes, diet and exercise practices) informed by gynaecological cancer literature. Previous attendance at screening was the used as a single item in analysis.	INCLUDED SUB-SCALES
Outcome variable			
Time to help-seeking	Self-measured	Time to help seeking will be assessed by specific questions mapping four points along the help-seeking journey to medical care for post-menopausal bleeding symptom(s) (first recognition of somatic change, recognition of concern, booking doctor's appointment, and attending doctor's appointment for symptom). Questions and associated Symptom Flow Chart follows the Anderson Delay Model (Anderson, Cacioppo & Roberts, 1995) Dates are be comprehensively acquired through the Flow Chart and associated questions.	
	Extended time	Extended time to help-seeking is defined by delaying help-seeking more than two weeks after detection of PMB and before attendance at a healthcare service.	√

APPENDIX F

Chapters 5 & 6: Full Questionnaire

Sandwell & West Birmingham Hospitals NHS Trust
UNIVERSITY OF BIRMINGHAM

Instructions for filling in the questionnaire

Before you begin this questionnaire booklet please write your full name in the upper right-hand corner of this page. If you have any difficulties completing this questionnaire or have any additional questions while completing this booklet please contact the lead researcher, Sara Tookey.

Primary Researcher: Sara Tookey
PhD Researcher
School of Psychology, University of Birmingham
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B15 2TT

This booklet consists of 12 pages consisting of 10 different sections. You will first be asked to answer questions about how you are feeling on an emotional level today. The following section will ask you about how feel about your body in a body image questionnaire. Questions relating to your social environment and community in which you live will be asked. After these sections have been completed the booklet will present you with questions related to your experiences with healthcare, gynaecological symptoms and your beliefs about health and illness. These sections will also ask you to explain how you came to seek help at the Post Menopausal Clinic today. The final section will ask you to fill out basic demographic questions.
After completing this booklet questionnaire you will be provided with a detachable debrief form (on the last page of the booklet) that you may take home with you. The debrief form will review with you the purpose of the study and provide you with additional contact details for any further questions and support.

Please place your completed booklets into the pre-paid envelope provided. You may place this directly into the post or deliver the sealed envelope to the Post Menopausal Clinic receptionist where it will be placed into the clinic mail to be sent directly to the Primary Researcher, Sara Tookey.

When working through this booklet please read the instructions provided for each section before answering the questions.

How are you feeling today?

The following questions are designed to understand your *current* emotions and feelings. Please tick the corresponding box to the right of each statement that best represents how you have been feeling in the *past week*. **Please tick only one box for each statement.**

1	I feel tense or 'wound up	Most of the time	A lot of the time	From time to time, occasionally	Not at all
2	I still enjoy the things I use to enjoy	Definitely as much	Not quite so much	Only a little	Hardly at all
3	I get a sort of frightened feeling as if something awful is about to happen	Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
4	I can laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all
5	Worrying thoughts go through my mind	A great deal of the time	A lot of the time	Not too often	Very little
6	I feel cheerful	Never	Not often	Sometimes	Most of the time
7	I can sit at ease and feel relaxed	Definitely	Usually	Not often	Not at all
8	I feel as if I am slowed down	Nearly all the time	Very often	Sometimes	Not at all
9	I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all	Occasionally	Quite often	Very often
10	I have lost interest in my appearance	Definitely	I don't take as much care as I should	I may not take quite as much care	I take just as much care as ever
11	I feel restless as if I have to be on the move	Very much indeed	Quite a lot	Not very much	Not at all
12	I look forward with enjoyment to things	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
13	I get sudden feelings of panic	Very often indeed	Quite often	Not very often	Not at all
14	I can enjoy a good book or radio or television programme	Often	Sometimes	Not often	Very seldom

How do you feel about your body?

We would like to know how you have been feeling about your appearance over the **PAST FOUR WEEKS**. Please read each question and tick the appropriate answer box to the right. Please answer all the questions.

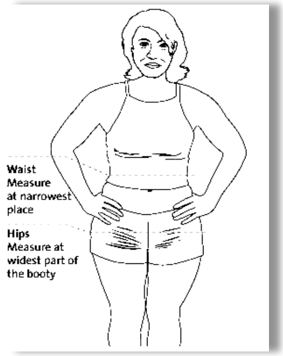
1	Has feeling bored made you brood about your shape?	Never	Rarely	Sometimes	Often	Very Often	Always
2	Have you thought that your thighs, hips or bottom are too large for the rest of you?	Never	Rarely	Sometimes	Often	Very Often	Always
3	Have you worried about your flesh being not firm enough?	Never	Rarely	Sometimes	Often	Very Often	Always
4	Have you felt so bad about your shape that you have cried?	Never	Rarely	Sometimes	Often	Very Often	Always
5	Have you avoided running because your flesh might wobble?	Never	Rarely	Sometimes	Often	Very Often	Always
6	Has being with thin women made you feel self-conscious about your shape?	Never	Rarely	Sometimes	Often	Very Often	Always
7	Have you worried about your thighs spreading out when sitting down?	Never	Rarely	Sometimes	Often	Very Often	Always
8	Has eating even a small amount of food made you feel fat?	Never	Rarely	Sometimes	Often	Very Often	Always
9	Have you avoided wearing clothes which make you particularly aware of the shape of your body?	Never	Rarely	Sometimes	Often	Very Often	Always
10	Has eating sweets, cakes, or other high calorie food made you feel fat?	Never	Rarely	Sometimes	Often	Very Often	Always
11	Have you felt ashamed of your body?	Never	Rarely	Sometimes	Often	Very Often	Always
12	Has worry about your shape made you diet?	Never	Rarely	Sometimes	Often	Very Often	Always
13	Have you felt happiest about your shape when your stomach has been empty (e.g. in the morning)?	Never	Rarely	Sometimes	Often	Very Often	Always
14	Have you felt that it is not fair that other women are thinner than you?	Never	Rarely	Sometimes	Often	Very Often	Always
15	Have you worried about your flesh being dimply?	Never	Rarely	Sometimes	Often	Very Often	Always
16	Has worry about your shape made you feel you ought to exercise?	Never	Rarely	Sometimes	Often	Very Often	Always

BSQ-16A © Evans & Dolan, 1993.

Measuring your hips and waist

It is now time to use the tape measure provided at the back of each flyer to measure your hips and waist in centimetres. Please carefully take the tape-measure out of the envelope. *Be careful not to tear it.* Please ensure that you are taking this measurement under your clothing unless you are wearing tight clothing.

Using the diagram below as a guide, please measure you waist and hips with your tape measure.



Waist Measurement: In centimetres

1) Take 4-5 consecutive natural breaths
2) Place the tape measure at the midpoint between the top of your hipbone and the lowest point of your rib. *(This is usually the narrowest part of your midsection)*
3) Try to ensure that your tape measure is directly across this middle section.

*If you are having difficulty please ask for assistance from another person.

Hip Measurement: In centimetres

1) Place the tape measure around the largest area of your buttocks and upper thigh.

My waist measurement in centimetres is: ________ *(take measurement to the nearest .5cm)*	**My hip measurement in centimetres is:** ________ *(take measurement to the nearest .5cm)*

PLEASE TELL US ABOUT YOUR SOCIAL NETWORK AND COMMUNITY

We are also interested to see how a person's social environment or community can impact health beliefs and behaviours. As such we are interested to hear how you experience your neighbourhood, community and your available social support. *Please indicate yes or no for the following items.*

Neighbourhood

I would like to start by asking you about the neighbourhood in which you live. Answer the following yes or no questions by ticking the boxes on the right.

Is it a place you enjoy living in?	○ Yes	○ No
Is it a place where you personally feel safe?	○ Yes	○ No
Is it a place where neighbours look after each other or not?	○ Yes	○ No
Has it good facilities for young children or not?	○ Yes	○ No
Has it good local transport or not?	○ Yes	○ No
Has it good leisure facilities for people like yourself or not?	○ Yes	○ No

Please tick yes or no for the following three statements to indicate if you have experienced any of the following in the last 12 months.

I have had a personal experience of theft, mugging, break-in or other crime.	○ Yes	○ No
I have had a personal experience of verbal abuse due to race or colour	○ Yes	○ No
I have had a personal experience of a physical attack due to race or colour	○ Yes	○ No

Community Activity

Have you done any of the following in the past fortnight? Please indicate yes or not by the following statements.

I attended an adult education or night-class course	○ Yes	○ No
I participated in a voluntary group or local community group	○ Yes	○ No
I participated in community or religious activities	○ Yes	○ No

How long have you lived in this area/neighbourhood?

○ 10 or more years ○ 4-9 years ○ 2-3 years ○ 1 year or less

Social Support

Please indicate yes or no for the following.

Do you have any close friends or close relatives that you see or speak to on a regular bases?	○ Yes	○ No

Please tick one circle which best describes these relationships?

- ○ Close contact with friends and relatives
- ○ Close contact with relatives only
- ○ Close contact with friends only
- ○ No close contact with friends/relatives

Have you done any of the following in the past fortnight? Please indicate yes or no by the following statements by ticking in the corresponding box.

Health History Questionnaire

	Yes	No
I visited relatives		
I had relatives visit me		
I have gone out with relatives		
I have spoken to relatives on the phone		

	Yes	No
I visited friends		
I had friends visit me		
I have gone out with friends		
I have spoken to friends on the phone		

We are interested to hear about your health practices and lifestyle choices. **Please indicate how much you agree or disagree with the statements by ticking the appropriate box.**

	Health History	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
1	I regularly attend the doctor for preventative screenings					
2	I eat healthily					
3	I exercise regularly					
4	I am a smoker					
5	I attend regularly scheduled mammograms					
6	I conduct regular breast self-checking behaviour					
7	My body weight is overweight or obese					
11	I have a chronic health condition that is different from the condition which has brought me in today					
12	I drink more than 4 drinks of alcohol in a day					

We are interested in your own personal views of how you now see the current medical problem that brought you into the clinic today. When we use the term ‘problem’ we are referring to the symptom or symptoms which you believe have brought you in to see us today**. Please indicate how much you agree or disagree with the following statements about the current medical problem that has brought you into the clinic today, and the associated symptom(s) you’ve been experiencing by ticking the appropriate box.**

	VIEWS ABOUT YOUR CURRENT MEDICAL PROBLEM	**Strongly Disagree**	**Disagree**	**Neither Agree Nor Disagree**	**Agree**	**Strongly Agree**
1	My current problem will last a short time					
2	My current problem is likely to be permanent rather than temporary					
3	My current problem has major consequences on my life					
4	There is nothing which can help my current problem					
5	My symptom(s) will last for a long time					
6	This symptom(s) will pass quickly					
7	I expect to have this symptom(s) for the rest of my life					
8	My current problem is a serious one					
9	My current problem does not have much effect on my life					
10	My current problem strongly affects the way others see me					
11	My current problem has serious financial consequences					
12	My current problem causes difficulties for those who are close to me					

	VIEWS ABOUT YOUR CURRENT MEDICAL PROBLEM	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
13	There is a lot which I can do to control symptoms					
14	The symptoms of my current problem are puzzling to me					
15	Nothing I do will affect my current problem in the future					
16	What I do can determine whether my current problem gets better or worse					
17	When I think about my current problem I get upset					
18	The negative effects of my current problem can be prevented (avoided) by medical care					
19	The course of my current problem depends on me					
20	My current problem is a mystery to me					
21	I have the power to influence my current problem now & for the future					
22	My actions will have no effect on future outcomes of my current problem					
23	My symptom(s) is very unpredictable					
24	I get depressed when I think about my current problem					
25	Medical care through the post-menopausal clinic can control my current problem					
26	My current problem will improve in time					
27	Having this current problem makes me feel anxious					
28	There is very little that can be done to improve my current problem					
29	My current problem does not worry me					
30	My symptom(s) come and go in cycles					
31	My current problem makes me feel angry					
32	Medical care will be effective in curing my current problem					
33	I don't understand my current problem					
34	My current problem makes me feel afraid					
35	My current problem doesn't make any sense to me					
36	I go through cycles in which my current problem gets better and worse					
37	I have a clear picture or understanding of my current problem					
38	The symptom(s) of my current problem change a great deal from day to day					

What do YOU think are the three main causes of your current medical problem?

1. ____

2. ____

3. ____

RISK FACTORS FOR GYNAECOLOGICAL CANCER

Up until now we have been interested in post-menopausal bleeding and symptoms you may have experienced related to this. We would like to ask you about gynaecological cancers in general. Gynaecological cancers are cancers that develop within a woman's reproductive system. Gynaecological cancer includes cancers of the cervix (cervical cancer), ovaries (ovarian cancer), womb (endometrial cancer or uterine cancer), genitals (vulvar cancer), or birth canal (vaginal cancer).

Please indicate if you believe that the following people could be at increased risk for developing gynaecological cancer(s) by an ticking in the YES or NO box.

	Which of the following are risk factors of gynaecological cancers	**YES**	**NO**
RF1	Women between the age of 50 and 60		
RF2	Women who meet criteria for obesity		
RF3	Women with high blood pressure		
RF4	Women with Polycystic Ovarian Syndrome		
RF5	Women who've birthed to more than 3 children		
RF6	Women who have never been pregnant		
RF7	Women who have taken birth control pills (contraceptives)		
RF8	Women who have taken hormone replacement therapy		
RF9	Women who have been infected by the Flu virus in the past 5 years		
RF10	Women with diabetes		
RF11	Women with a family history of other cancers (not gynaecologic)		
RF12	Women a history of multiple sexual partners		
RF13	Women with mutations in the genes BRCA1 and BRCA2		
RF14	Women with poor oral hygiene		
RF15	Women with a history of human papilloma virus HPV infection		
RF16	Women who smoke cigarettes		
RF17	Women who have had their first pregnancy after 20 years old		
RF18	Women with prior cancer diagnosis		
RF19	Women who have experienced late menopause		
RF20	Women who have experienced infertility		

Have you ever felt at higher risk of disease than others around you?

○ Yes ○ No

When you first sought help how much more or less did you think you were at risk of developing cancer than others around you?

○ More at risk	○ At similar risk to others	○ Less at risk

Currently how much do you think you are at risk of being diagnosed with a cancer than others?

○ More at risk	○ At similar risk to others	○ Less at risk

SYMPTOMS OF GYNAECOLOGICAL CANCER

Below is a list of symptoms that may or may not be related to gynaecological cancer. **Please indicate if you believe they are symptoms of gynaecological cancer or not.**

Abdominal bloating	☐ Yes	☐ No
Loss of appetite/weight	☐ Yes	☐ No
Constipation	☐ Yes	☐ No
Severe or recurrent headaches	☐ Yes	☐ No
Changes in bowel or bladder habits	☐ Yes	☐ No
Fatigue	☐ Yes	☐ No
Vaginal discharge	☐ Yes	☐ No
Numbness of fingers and toes	☐ Yes	☐ No
Indigestion	☐ Yes	☐ No
Lower Abdominal Pain	☐ Yes	☐ No
Pain during intercourse	☐ Yes	☐ No
Unexplained Weight gain/increased waist size	☐ Yes	☐ No
Lower back pain	☐ Yes	☐ No
Cough	☐ Yes	☐ No
Vaginal Pain	☐ Yes	☐ No
Vaginal Ulcers	☐ Yes	☐ No
Lump or wart-like growth on vulvar	☐ Yes	☐ No

Your Journey to the Clinic

The next section will be used to map out your journey from the moment you noticed a symptom until the day that brought you into the Post-menopausal Bleeding Clinic for your first appointment. **For each question please indicate to the best of your knowledge the date, season, and year when you recall having these experiences.**

1) When did you first begin to notice that there was a change(s)/symptom(s) in your body?

   Date:____________ (dd/mm/yyyy) Season:___________
   1.a. What bodily change did you experience?

2) When did you first realise that the symptom(s)/changes(s) was something to be concerned about?

   Date:____________ (dd/mm/yyyy) Season:___________
   2.a. Please explain why you felt the symptom was something to be concerned about?

3) Please begin Symtpom Flow Chart on next page. The flow chart wil ask you questions related to the symptom(s)/change(s) which has brought you into the post-menopausal clinic.

Protocol V1.8 10/04/13

BEGIN HERE

1 When did you first notice your post-menopausal bleeding symptom?

(Write in box)
Date: day/month/year

2 What did you do in response to this? (select all that apply)

- ○ I looked up the symptom online
- ○ I remedied the problem with over-the-counter medicine or an alternative approach to medicine (aromatherapy, acupuncture, psychotherapy, etc.)
- ○ I confided in another person
- ○ I monitored my symptoms to see if they would improve or worsen
- ○ I tried not to think about it
- ○ I assumed it was normal
- ○ I assumed it was due to another condition I have (diabetes, arthritis, anaemia, etc.)
- ○ I altered my diet and/or exercise
- ○ I consulted a pharmacist
- ○ I contacted a healthcare professional
- ○ Other

2a If 'I confided in another person', from whom did you first confide in /seek advice?

- ○ A family member
- ○ A significant other
- ○ A friend
- ○ A health care professional
- ○ A pharmacy shop assistant or pharmacist
- ○ An online help source
- ○ Other

2b If Other, what please write what you did in box below

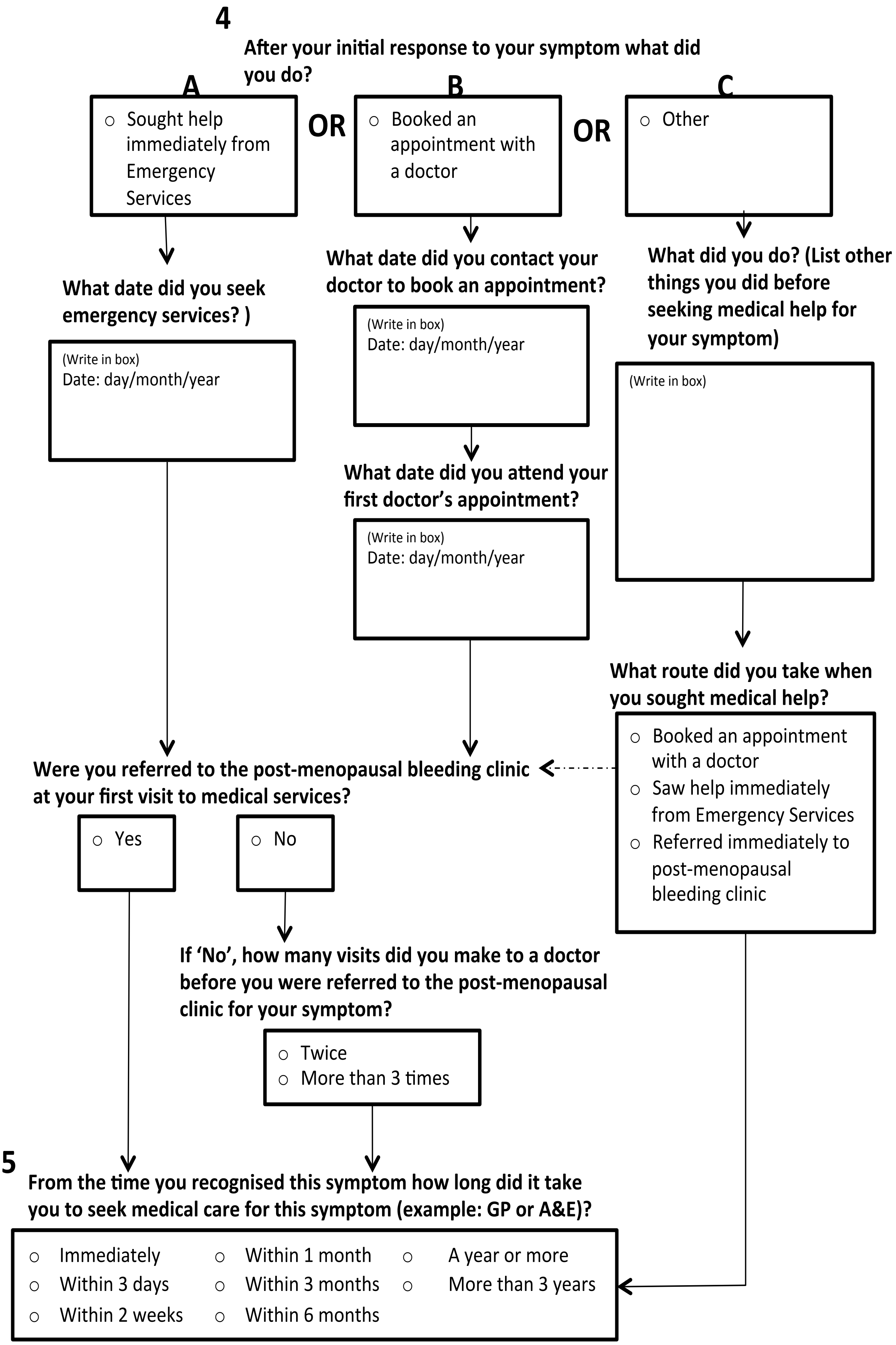
(Write in box)

3 Did these work?

- ○ Yes
- ○ No *(Move to next page)*

3a If Yes, how long did this relief generally last?

- ○ Less than two days
- ○ A week or more
- ○ A month or more
- ○ More than 3 months
- ○ More than 6 months
- ○ For one year
- ○ For a year or more
- ○ For more than 2 years



4

After your initial response to your symptom what did you do?

A

- ○ Sought help immediately from Emergency Services

OR

B

- ○ Booked an appointment with a doctor

OR

C

- ○ Other

What date did you seek emergency services?)

(Write in box)
Date: day/month/year

What date did you contact your doctor to book an appointment?

(Write in box)
Date: day/month/year

What date did you attend your first doctor's appointment?

(Write in box)
Date: day/month/year

What did you do? (List other things you did before seeking medical help for your symptom)

(Write in box)

What route did you take when you sought medical help?

- ○ Booked an appointment with a doctor
- ○ Saw help immediately from Emergency Services
- ○ Referred immediately to post-menopausal bleeding clinic

Were you referred to the post-menopausal bleeding clinic at your first visit to medical services?

- ○ Yes
- ○ No

If 'No', how many visits did you make to a doctor before you were referred to the post-menopausal clinic for your symptom?

- ○ Twice
- ○ More than 3 times

5

From the time you recognised this symptom how long did it take you to seek medical care for this symptom (example: GP or A&E)?

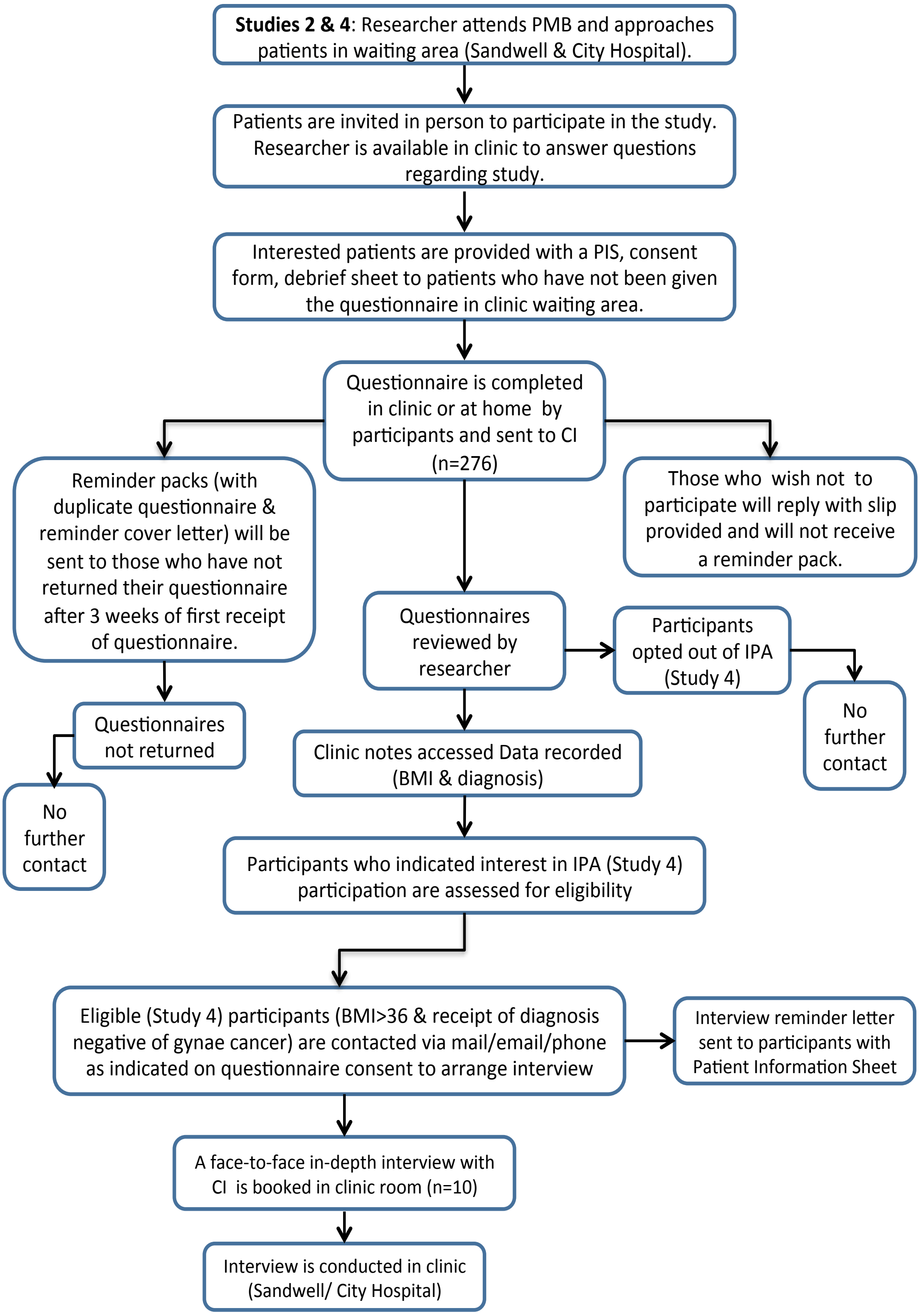
○ Immediately	○ Within 1 month	○ A year or more
○ Within 3 days	○ Within 3 months	○ More than 3 years
○ Within 2 weeks	○ Within 6 months	

Basic demographic questions

What is your date of birth?	__________ dd/mm/yy			
What is your gender?	o Male	o Female		
What is the highest level of education you have completed?	o Less than compulsory for UK education standards (Did not complete school education)	o Compulsory levels of education (Primary and secondary education up ages 16-18)	o Above compulsory levels of education (Higher education Bachelor's degree, other tertiary education)	o Further post graduate education (Masters, Doctorate, etc.)
What is your employment status?	o Currently employed o Homemaker	o Sick leave o Retired	o Student o Self-employed	o Unemployed
What is your current marital status?	o Single, never married o Live with long-term partner	o Married o Widowed	o Separated	o Divorced
Please indicate if you identify with any of the following statements	o I have no central heating in the household o I have no car available	o I do not own a home o I have no telephone	o I receive income support/social security benefit	O none
What is your Ethnicity/Race (please select all that apply):	o *White* o British o Irish o Eastern European o Other White:	o Black Caribbean o Black African o Black British o White and Asian o Other Mixed	o *Chinese or other ethnic groups* o *Other ethnic group(s):* ________________	o *South Asian or Asian British* o Indian o Pakistani o Bangladeshi o Other Asian
What is you religious affiliation?	o Catholic o Christian	o Jewish o Muslim	o Hindu o Buddhist	o None o Other:
What is your country of origin or birth?	____________________			
If you have moved to the UK from another country, when did you arrive in the UK to live?	mm/yy ________/_________			
Languages commonly spoken (please select all that apply):	o English o Pahari o Punjabi o Sindhi o Bengali o Sylheti o Arabic	o Urdu o Japanese o Chinese o Swahili o Hausa o Eastern European	o Hindi o Pashto o Gujarati o Mirpuri o Kutchhi o Other: ______________	
Please indicate who in your family speaks/spoke English (<u>select all that apply</u>):	o Self	o Parent(s)	o Grandparent(s)	o Great-grandparent(s)

APPENDIX G

Chapters 5 & 7: Study Design Flow Chart



Studies 2 & 4: Researcher attends PMB and approaches patients in waiting area (Sandwell & City Hospital).

Patients are invited in person to participate in the study. Researcher is available in clinic to answer questions regarding study.

Interested patients are provided with a PIS, consent form, debrief sheet to patients who have not been given the questionnaire in clinic waiting area.

Questionnaire is completed in clinic or at home by participants and sent to CI (n=276)

Reminder packs (with duplicate questionnaire & reminder cover letter) will be sent to those who have not returned their questionnaire after 3 weeks of first receipt of questionnaire.

Questionnaires not returned

No further contact

Those who wish not to participate will reply with slip provided and will not receive a reminder pack.

Questionnaires reviewed by researcher

Participants opted out of IPA (Study 4)

No further contact

Clinic notes accessed Data recorded (BMI & diagnosis)

Participants who indicated interest in IPA (Study 4) participation are assessed for eligibility

Eligible (Study 4) participants (BMI>36 & receipt of diagnosis negative of gynae cancer) are contacted via mail/email/phone as indicated on questionnaire consent to arrange interview

Interview reminder letter sent to participants with Patient Information Sheet

A face-to-face in-depth interview with CI is booked in clinic room (n=10)

Interview is conducted in clinic (Sandwell/ City Hospital)

APPENDIX H

Chapters 5 & 6: Information Sheet for Participants

Sandwell & West Birmingham Hospitals NHS
NHS Trust
UNIVERSITY OF BIRMINGHAM

Location: Sandwell Hospital PMB Clinic

Sheet for Participants (Phase 1)

Study Title: *Help-seeking for gynaecological symptoms: A Questionnaire study*

Introduction:
My name is Sara Tookey and I am Doctoral Researcher at the University of Birmingham. I would like to invite you to take part in a study about your experience of seeking help for your gynaecological symptoms, from the moment you recognised that something was not right, until now. Please take the time to read through the following information. Ask a staff member or researcher if you have any questions or would like more information.

What is the purpose of the study?
The purpose of the study is to gain an understanding of the things that lead women to seek help for gynaecological symptoms as well as the things that get in the way of seeking help. We'd like to know how this process has been for you. How did you get the advice or help you needed when you noticed the symptom? When did you decide to see a healthcare professional?

The study is in the form of a paper questionnaire pack. It will take 30-40 mins to complete. Paper questionnaire packets are available in the clinic.

Why have I been chosen?
Any woman who attends the Post-menopausal Bleeding Clinic is eligible to participate in this study.

Do I have to take part? / What happens if I take part?
It is entirely up to you whether you decide to take part in the study or not. If you participate in the questionnaire you will be asked about your health beliefs and your experience of help seeking before attending the Post-menopausal Bleeding Clinic in Birmingham. In this questionnaire you will also be asked questions about your knowledge of gynaecological cancers. Please do not worry about this, we just want to gain a better understanding of all patients who attend the clinic. No information you provide will be linked to your medical notes and your decision to participate in this study will not impact your care in any way. If you do feel distressed at any point regarding the process of filling in the questionnaire you may contact the researcher or discuss this with a clinic staff and appropriate action will be taken according to the PMB clinic policy.

We will ask you to allow us to access your chart notes at two time points during the study (Initial clinic visit and 6 month follow-up to confirm any diagnosis) and your name and date will be required for accessing this information. Your chart will be accessed solely for the purpose of obtaining height, weight and per cent body fat, which will have been measured by medical personnel at the time of initial clinic visit. The second time we access your notes will be to confirm the diagnosis (if any) given in clinic. Hospital Trust policies will be followed in accessing clinic notes and no identifiable information will be linked to your questionnaire responses.

On the consent form for this study you will also be asked if you wish to be contacted for a possible participation a future phase 2 study (consent for this is optional).
Even if you decide to take part, you are free to withdraw at any time up until a month after completion of

the questionnaire without having to give any reason. Withdrawing from the study will not affect you or have any negative consequences on your circumstances. All the information you provided for the study will be destroyed and will no longer be part of the results of the study.

What happens to my information?
All information that is obtained from the questionnaire will be stored in a locked filing cabinet at the University of Birmingham where only the study researchers will have access to this information and will be assigned a unique number code that cannot not be traced back to you or anyone else. Your name will only appear on your consent form, and the researcher will be the only person who has access to a list linking your name with your number. All data will be stored securely at the University according to the University of Birmingham's Code of Practice for Research for 10 years. Your clinic chart will be accessed twice (as stated above). NHS trust policies will be followed in accessing clinic notes and no identifying data will be linked with the data.

Will my taking part in this study be kept confidential?
Yes. All information that is obtained from the study will be kept strictly confidential. No identifiable information will be included in any publication using the data of this study. Good Clinical Practice codes will be followed and any concerns will be reported to clinic staff member to determine appropriate action.

What will happen to the results of the study?
The results of the study may be presented at a conference or published in an academic journal and may be used to inform future research regarding seeking help for potential symptoms of gynaecological cancer. Again, no identifiable information will be released in any write-up of the results. If you choose to participate in the study you may request to receive a copy of the results by contacting the researcher.

Please contact SWBH Patient PALS advice and liaison service (PALS) for hospital/trust assistance you have concerns or complaints regarding this research: 0121 507 5836

Please contact **Sara Tookey** with any questions you may have.

Primary Researcher: **Sara Tookey** **PhD Researcher** **School of Psychology** **University of Birmingham** **Edgbaston, Birmingham** **B15 2TT;**	Supervisory Researcher: Dr. Beth Grunfeld Senior Lecturer and Research Supervisor School of Psychology University of Birmingham Edgbaston, Birmingham B15 2TT;
Consultant Supervisor at Clinic: **Mr. Joe Kabukoba, MD** **Post-menopausal Clinic Consultant** **Sandwell Hospital** **Sandwell & West Birmingham Hospitals NHS Trust**	Consultant Supervisor at Clinic: Mrs. Shagaf Bakour, MD Consultant Gynaecologist, Birmingham City Hospital Sandwell and West Birmingham Hospitals NHS

If you wish not to participate please remove the below slip and you will not receive a reminder packet in three weeks time.

I, ______________________________ (insert full name here) wish not to participate in the *Help-seeking for gynaecological symptoms: A Questionnaire study*. Please do not contact me in the future regarding taking part in this study.

APPENDIX I

Chapters 5 & 6: Consent Form for Participants

Sandwell & West Birmingham Hospitals NHS Trust NHS UNIVERSITY OF BIRMINGHAM

Sandwell/City Hospital PMB Clinic: Health beliefs and help-seeking for gynaecological symptoms: A Questionnaire study

Consent Form for Participants

Please tick each statement to the left AND initial to the right of each statement indicate agreement.

☐ I have read and understood the information sheet for the above study and have been given the opportunity to ask questions. _______

☐ I understand that my participation is voluntary and that I am free to withdraw from the study up until 2 months without having to give any reason and without me being affected or this having any negative consequences on my circumstances. _______

☐ I agree to provide information that will be used for research purposes only, and understand that all the information relating to myself obtained as part of the study will be strictly confidential, and that I will not be personally identified in any write-up of the results. _______

☐ I understand that relevant data collected during the study may be looked at by individuals from the University of Birmingham's Psychology research team, and from regulatory authorities of the NHS Trust , where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. _______

☐ I understand that information will be stored in secured manual and electronic files and is subject to the provisions of the Data Protection Act. _______

☐ I consent to the researcher accessing my patient notes twice to retrieve the following information: Height, weight, % body fat, and hip-to-waist ratio if available, and investigation results/diagnosis received up to 6 months after interview and I understand that I must provide my name and date of birth for access. _______

☐ I wish to participate in this study under the conditions set out here and in the Information Sheet for Participants. _______

Optional consent for future contact:

We are also interested in finding out more about the experience of help-seeking for post-menopausal bleeding symptoms through an in-depth conversational interview. In principle would you object to being contacted to participate in a Phase 2 of this study within the next 12 months? Please indicate by ticking and providing your preferred contact information below.

☐ I would not object to future participation. Contact Details:______________________

☐ I would like to receive a summary of the study results. ____________________________

Printed Name: ______________________ **Participant Signature:** ______________________

Date of Birth: ________________________ **Date Agreed:** ______________________________

APPENDIX J

Chapters 5 & 6: Debrief Form for Participants

Sandwell & West Birmingham Hospitals NHS Trust NHS UNIVERSITY OF BIRMINGHAM

Sandwell/City Hospital PMB Clinic: **Debrief form (Questionnaire Study)**

Study Title: *Help-seeking for gynaecological symptoms: A Questionnaire study*
Thank you for choosing to participate in this research study

PARTICIPANT'S COPY: You may keep this debrief form for your own records

Thank you for agreeing to participate in this study investigating the experience of seeking help for your gynaecological symptoms. We asked you questions about your own journey from the moment you noticed the bodily change (a symptom) to your attendance at the Post-menopausal clinic.

The results of the study will be used to see if there are certain factors that may predict how quickly an individual seeks help for abnormal gynaecological symptoms. Factors being investigated included: (a) demographic factors, (c) ethnic and cultural factors, (d) previous health behaviours, (e) knowledge of symptoms and risks for disease, (f) weight and size, (g) using social network for support, (h) body size/shape satisfaction. It is important to understand how women seek help for gynaecological symptoms so that we may be able to implement an intervention to encourage women to seek help more quickly.

If you would like to speak with someone about any concerns which may have been brought to light by this research please speak with a clinic staff member. Any questions regarding the research please contact the researchers below.

What next?
Your study participation is complete. We will access your chart notes through the clinic and will acquire your weight and height and body fat percentage which is measured by the clinic healthcare professional. In the next six months the researcher will access your chart notes once more to document your diagnosis.

Even if you decided to take part, you are still free to withdraw from the study at any time up until **a month post after completion of the questionnaire**, without having to give any reason. Withdrawing from the study will not affect you or have any negative consequences on your circumstances. If you wish to withdraw please contact the researcher below (Sara Tookey).

What happens to my information?
All information that is obtained from the questionnaire will uploaded onto a password-protected computer and paper questionnaires will be stored in a locked filing cabinet at the University of Birmingham where only the study researchers will have access to this information. Your questionnaire dose not have your name on it, this will be on the separate

instructions page only, which will be kept separate from your completed questionnaire. This information will then be entered into a computer database, where your information will be assigned a number. The information in the database, as well as all study material will be identified by numbers, and can therefore not be traced back to you or anyone else. Your name will only appear on your consent form, and the researcher will be the only person who has access to a list linking your name with your number.

Your clinic chart will be accessed twice (as stated above). Your personal information will not be linked to the data at any time and will be coded so that you will not be identifiable in the study data. NHS trust policies will be followed in accessing clinic notes and no identifying data will be linked with the data.
All data will be stored securely at the University according to the University of Birmingham's Code of Practice for Research for 10 years.

Will my taking part in this study be kept confidential?
Yes. All information that is obtained during the course of the study will be kept strictly confidential. No identifiable information will be included in any publication using the data of this study. Good Clinical Practice codes will be followed and if you should happen to disclose intent to harm yourself or others, a clinic staff member will be informed and clinic/trust policy will determine appropriate safety response action.

What will happen to the results of the study?
The results of the study will be analysed by the research team to identify the barriers to help-seeking for women who have sought help for abnormal gynaecological symptoms and will explore factors that may impact process of coming to seek help for such symptoms. The results may be presented at a conference or published in an academic journal and may be used to inform future research regarding the experience of help seeking for post-menopausal bleeding. Please note that no identifiable information will be released in any write-up of the results. If you choose to participate in the study you may request to receive a copy of the results by contacting the researcher.
Please contact SWBH Patient PALS advice and liaison service (PALS) for hospital/trust assistance you have concerns or complaints regarding this research: 0121 507 5836

Primary Researcher: **Sara Tookey** PhD Researcher School of Psychology University of Birmingham Edgbaston, Birmingham B15 2TT;	Supervisory Researcher: Dr. Beth Grunfeld Senior Lecturer and Research Supervisor School of Psychology University of Birmingham Edgbaston, Birmingham B15 2TT
Consultant Supervisor at Clinic: Mr. Joe Kabukoba, MD Post-menopausal Clinic Consultant Sandwell Hospital Sandwell & West Birmingham Hospitals NHS Trust	Consultant Supervisor at Clinic: Mrs. Shagaf Bakour, MD Consultant Gynaecologist, Birmingham City Hospital Sandwell and West Birmingham Hospitals NHS

APPENDIX K

Chapter 5: Reliability Statistics of Measures

Body shape questionnaire-16A (BSQ-16A)

Reliability Statistics

Cronbach's Alpha	N of Items
0.94	16

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
BSQ16A1	36.45	283.146	0.613	0.938
BSQ16A2	36.25	269.969	0.727	0.935
BSQ16A3	36.02	274.036	0.671	0.937
BSQ16A4	37.16	283.454	0.686	0.936
BSQ16A5	37.27	284.817	0.594	0.938
BSQ16A6	36.83	275.406	0.766	0.934
BSQ16A7	36.98	276.048	0.742	0.935
BSQ16A8	37.04	283.047	0.649	0.937
BSQ16A9	35.95	273.998	0.699	0.936
BSQ16A10	36.39	273.234	0.739	0.935
BSQ16A11	36.52	268.142	0.812	0.933
BSQ16A12	36.3	274.609	0.675	0.937
BSQ16A13	36.37	287.688	0.442	0.942
BSQ16A14	37.04	278.871	0.687	0.936
BSQ16A15	37.05	280.294	0.698	0.936
BSQ16A16	36.03	272.732	0.737	0.935

IPQ-R: Subscale 'Timeline'

Reliability Statistics

Cronbach's Alpha	N of Items
0.738	6

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
IP2Timeline	12.3	12.467	0.521	0.687
IP6RTimeline	11.94	12.558	0.513	0.69
IP26RTimeline	12.41	16.15	0.138	0.776
IP1RTimeline	11.95	13.436	0.38	0.729
IP5Timeline	12.45	11.664	0.658	0.644
IP7Timeline	12.72	11.98	0.637	0.653

IPQ-R: Subscale 'Timeline Cyclical'

Reliability Statistics

Cronbach's Alpha	N of Items
0.591	4

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
IP23TimelineCyclical	8.16	8.683	0.065	0.721
IP30TimelineCyclical	8.62	5.667	0.54	0.375
IP36TimelineCyclical	8.85	5.865	0.489	0.42
IP38TimelineCyclical	9.01	6.387	0.44	0.467

IPQ-R: Subscale ‘Consequences’

Reliability Statistics

Cronbach's Alpha	N of Items
0.649	6

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
IP9RConsequences	11.03	13.987	0.178	0.687
IP3Consequences	11.45	11.606	0.484	0.562
IP8Consequences	11.53	12.87	0.438	0.585
IP10Consequences	12.37	13.087	0.497	0.572
IP11Consequences	12.4	14.429	0.309	0.629
IP12Consequences	11.85	11.872	0.43	0.586

IPQ-R: Subscale ‘Illness Coherence’

Reliability Statistics

Cronbach's Alpha	N of Items
0.805	5

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
IP14RIllnessCoherence	12.43	15.174	0.572	0.775
IP20RIllnessCoherence	12.54	14.96	0.67	0.743
IP35RIllnessCoherence	12.14	15.582	0.637	0.754
IP33RIllnessCoherence	12.13	14.99	0.691	0.736
IP37IllnessCoherence	12.15	17.767	0.397	0.822

IPQ-R: Subscale ‘Personal Control’

Reliability Statistics

Cronbach's Alpha	N of Items
.472	6

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
IP13PeronalControl	14.99	10.794	.234	.427
IP15RPersonalControl	14.32	12.172	.058	.516
IP16PersonalControl	14.63	9.611	.403	.330
IP19PersonalControl	14.83	9.718	.379	.343
IP21PersonalControl	14.60	9.007	.464	.285
IP22RPersonalControl	14.29	12.994	-.056	.574

IPQ-R: Subscale ‘Treatment Control’

Reliability Statistics

Cronbach's Alpha	N of Items
0.648	5

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
IP4RTreatmentControl	14.45	8.51	0.242	0.674
IP28RTreatmentControl	14.58	8.435	0.295	0.645
IP32TreatmentControl	14.71	7.511	0.515	0.542
IP25TreatmentControl	14.59	7.367	0.571	0.517
IP18TreatmentControl	14.78	7.772	0.426	0.583

IPQ-R: Subscale 'Emotional Representations'

Reliability Statistics

Cronbach's Alpha	N of Items
0.835	6

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
IP29REmotionalRep	14.17	27.441	0.413	0.845
IP17EmotionalRep	14.5	24.132	0.664	0.797
IP24EmotionalRep	14.68	22.612	0.738	0.78
IP27EmotionalRep	14.15	24.115	0.677	0.795
IP31EmotionalRep	15.06	26.877	0.456	0.837
IP34EmotionalRep	14.57	23.294	0.715	0.786

'Symptoms' Knowledge

Reliability Statistics

Cronbach's Alpha	N of Items
0.501	17

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Symptoms1	10.16	5.63	0.234	0.471
Symptoms2	10.11	5.354	0.395	0.436
Symptoms3	10.34	5.599	0.221	0.473
Symptoms4	10.09	6.547	-0.162	0.55
Symptoms5	10.06	5.57	0.319	0.455
Symptoms6	10.49	7.009	-0.342	0.589
Symptoms7	10.6	7.046	-0.377	0.584
Symptoms8	10.01	6.195	0.02	0.511
Symptoms9	10.56	6.082	0.041	0.512
Symptoms10	10.01	5.509	0.409	0.442
Symptoms11	10.07	5.238	0.491	0.418
Symptoms12	10.26	5.415	0.309	0.452
Symptoms13	10.18	5.416	0.329	0.448
Symptoms14	10.16	6.466	-0.13	0.548
Symptoms15	10.02	5.213	0.572	0.408
Symptoms16	10.15	5.215	0.445	0.422
Symptoms17	10.09	5.489	0.341	0.449

‘Risk-Factors’ Knowledge

Reliability Statistics

Cronbach's Alpha	N of Items
0.539	20

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
RF1	11.95	7.153	0.293	0.508
RF2	12.03	6.688	0.451	0.477
RF3	12.32	6.89	0.307	0.5
RF4	12.01	6.888	0.376	0.492
RF5	11.99	8.348	-0.24	0.589
RF6	12.4	6.975	0.29	0.504
RF7	12.33	8.658	-0.331	0.614
RF8	12.09	7.215	0.195	0.522
RF9	11.86	8.106	-0.148	0.564
RF10	12.38	7.058	0.251	0.512
RF11	11.97	7.086	0.31	0.504
RF12	12.06	6.91	0.337	0.497
RF13	12.05	6.681	0.443	0.477
RF14	12.09	8.427	-0.259	0.599
RF15	12.01	6.814	0.411	0.485
RF16	11.98	7.049	0.318	0.503
RF17	11.93	8.225	-0.197	0.578
RF18	11.91	7.24	0.291	0.51
RF19	12.41	7.212	0.195	0.522
RF20	12.54	7.144	0.287	0.508

Mood HADS: ‘Anxiety’ Subscale

Reliability Statistics

Cronbach's Alpha	N of Items
0.862	7

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
HADS1A	7.34	19.929	0.598	0.847
HADS3A	7.32	18.04	0.731	0.828
HADS5A	7.12	18.824	0.673	0.837
HADS7A	7.51	20.692	0.598	0.848
HADS9A	7.48	20.168	0.672	0.839
HADS11A	7.2	19.65	0.486	0.867
HADS13A	7.39	18.656	0.711	0.831

Mood HADS: 'Anxiety' Subscale

Reliability Statistics

Cronbach's Alpha	N of Items
0.785	7

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
HADS2D	4.18	10.235	0.473	0.765
HADS4D	4.3	10.139	0.557	0.751
HADS6D	4.23	9.983	0.575	0.747
HADS8D	3.54	9.75	0.481	0.765
HADS10D	4.26	9.779	0.528	0.755
HADS12D	4.08	9.346	0.594	0.741
HADS14D	4.42	10.684	0.384	0.781

Social Capital: Subscale 'Neighbourhood Crime' and Safety

Reliability Statistics

Cronbach's Alphaa	N of Items
-0.03	3

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Neighbourhood7	-0.02	0.028	-0.026	0.018
Neighbourhood8	-0.07	0.103	-0.035	0.018
Neighbourhood9	-0.1	0.115	0.023	-.063a

Social Capital: Subscale 'Community Engagement' Reliability Statistics

Reliability Statistics

Cronbach's Alpha	N of Items
0.208	4

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
CommunityActivity1	2.95	0.992	0.265	0.079
CommunityActivity2	2.93	0.915	0.25	0.04
CommunityActivity3	2.8	0.851	0.125	0.133
CommunityActivity4	0.37	0.626	-0.028	0.527

HHQ: Subscale ‘Previous Health Behaviours’

Reliability Statistics

Cronbach's Alpha	N of Items
0.259	3

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
HHQ1	7.43	3.122	0.111	0.262
HHQ2	7.25	3.986	0.102	0.262
HHQ6	7.35	2.666	0.216	-.006a

a The value is negative due to a negative average covariance among items. This violates reliability model assumptions. You may want to check item codings.

HHQ: Subscale ‘Health Promoting Behaviours’

Reliability Statistics

Cronbach's Alpha	N of Items
0.529	2

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
HHQ2	3.15	1.748	0.375	.
HHQ3	3.77	0.97	0.375	.

HHQ: Subscale ‘Health Harming Behaviours’

Reliability Statistics

Cronbach's Alphaa	N of Items
-0.424	2

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
HHQ4R	1.56	1.271	-0.179	.
HHQ9R	4.27	1.943	-0.179	.

APPENDIX L

Chapter 5: Frequency table- Data Screening

Time to help-seeking Frequency Table

	Frequency	%	Valid %	Cumulative %
0	9	5.5	5.5	5.5
1	4	2.4	2.4	7.9
2	11	6.7	6.7	14.6
3	16	9.8	9.8	24.4
4	4	2.4	2.4	26.8
5	4	2.4	2.4	29.3
6	10	6.1	6.1	35.4
7	13	7.9	7.9	43.3
9	4	2.4	2.4	45.7
10	2	1.2	1.2	47.0
11	1	.6	.6	47.6
13	1	.6	.6	48.2
14	14	8.5	8.5	56.7
15	1	.6	.6	57.3
16	4	2.4	2.4	59.8
17	2	1.2	1.2	61.0
18	2	1.2	1.2	62.2
19	2	1.2	1.2	63.4
20	2	1.2	1.2	64.6
21	3	1.8	1.8	66.5
23	1	.6	.6	67.1
28	3	1.8	1.8	68.9
30	6	3.7	3.7	72.6
33	2	1.2	1.2	73.8
35	1	.6	.6	74.4
37	1	.6	.6	75.0
44	2	1.2	1.2	76.2
45	1	.6	.6	76.8
60	2	1.2	1.2	78.0
61	1	.6	.6	78.7
62	1	.6	.6	79.3
66	1	.6	.6	79.9
70	2	1.2	1.2	81.1
72	1	.6	.6	81.7
76	1	.6	.6	82.3
79	1	.6	.6	82.9

80	2	1.2	1.2	84.1
84	1	.6	.6	84.8
89	1	.6	.6	85.4
98	1	.6	.6	86.0
116	1	.6	.6	86.6
118	1	.6	.6	87.2
122	1	.6	.6	87.8
158	1	.6	.6	88.4
162	1	.6	.6	89.0
180	2	1.2	1.2	90.2
218	1	.6	.6	90.9
245	1	.6	.6	91.5
251	1	.6	.6	92.1
278	1	.6	.6	92.7
305	1	.6	.6	93.3
360	1	.6	.6	93.9
400	1	.6	.6	94.5
720	2	1.2	1.2	95.7
780	1	.6	.6	96.3
930	1	.6	.6	97.0
1800	1	.6	.6	97.6
1810	1	.6	.6	98.2
2880	1	.6	.6	98.8
3031	1	.6	.6	99.4
3960	1	.6	.6	100.0
Total	164	100.0	100.0	

HADS: Subscale 'Anxiety' Frequency Table

	Frequency	%	Valid %	Cumulative %
0	7	4.3	4.3	4.3
1	7	4.3	4.3	8.6
1	1	.6	.6	9.2
2	7	4.3	4.3	13.5
3	5	3.0	3.1	16.6
4	8	4.9	4.9	21.5
5	10	6.1	6.1	27.6
6	2	1.2	1.2	28.8
6	13	7.9	8.0	36.8
7	19	11.6	11.7	48.5
8	13	7.9	8.0	56.4
8	1	.6	.6	57.1
9	11	6.7	6.7	63.8
10	10	6.1	6.1	69.9
11	5	3.0	3.1	73.0
12	7	4.3	4.3	77.3
13	8	4.9	4.9	82.2
14	5	3.0	3.1	85.3
15	3	1.8	1.8	87.1
16	7	4.3	4.3	91.4
17	5	3.0	3.1	94.5
18	4	2.4	2.5	96.9
19	3	1.8	1.8	98.8
20	1	.6	.6	99.4
21	1	.6	.6	100.0
Total	163	99.4	100.0	
Missing	1	.6		
	164	100.0		

HADS: Subscale 'Depression' Frequency Table

	Frequency	%	Valid %	Cumulative %
0	16	9.8	9.8	9.8
1	25	15.2	15.3	25.2
2	14	8.5	8.6	33.7
2	1	.6	.6	34.4
3	18	11.0	11.0	45.4
4	1	.6	.6	46.0
4	7	4.3	4.3	50.3
5	1	.6	.6	50.9
5	14	8.5	8.6	59.5
6	10	6.1	6.1	65.6
7	10	6.1	6.1	71.8
8	15	9.1	9.2	81.0
9	8	4.9	4.9	85.9
10	8	4.9	4.9	90.8
11	1	.6	.6	91.4
11	6	3.7	3.7	95.1
12	1	.6	.6	95.7
12	3	1.8	1.8	97.5
13	2	1.2	1.2	98.8
14	1	.6	.6	99.4
20	1	.6	.6	100.0
Total	163	99.4	100.0	
Missing	1	.6		
	164	100.0		

IPQ-R: Subscale 'Timeline' Frequency Table

	Frequency	%	Valid %	Cumulative %
8	2	1.2	1.2	1.2
9	1	.6	.6	1.8
10	7	4.3	4.3	6.1
11	2	1.2	1.2	7.3
11	9	5.5	5.5	12.8
12	9	5.5	5.5	18.3
13	18	11.0	11.0	29.3
14	24	14.6	14.6	43.9
15	18	11.0	11.0	54.9
16	1	.6	.6	55.5
16	23	14.0	14.0	69.5
17	18	11.0	11.0	80.5
18	13	7.9	7.9	88.4
19	6	3.7	3.7	92.1
20	4	2.4	2.4	94.5
21	3	1.8	1.8	96.3
22	1	.6	.6	97.0
23	2	1.2	1.2	98.2
24	2	1.2	1.2	99.4
26	1	.6	.6	100.0
Total	164	100.0	100.0	

IPQ-R: Subscale' Timeline Cyclical' Frequency Table

	Frequency	%	Valid %	Cumulative %
4	3	1.8	1.9	1.9
5	1	0.6	0.6	2.5
6	7	4.3	4.3	6.8
7	9	5.5	5.6	12.3
8	9	5.5	5.6	17.9
9	12	7.3	7.4	25.3
10	20	12.2	12.3	37.7
11	2	1.2	1.2	38.9
11	16	9.8	9.9	48.8
12	22	13.4	13.6	62.3
13	13	7.9	8.0	70.4
14	19	11.6	11.7	82.1
15	13	7.9	8.0	90.1
16	9	5.5	5.6	95.7
17	1	0.6	0.6	96.3
18	1	0.6	0.6	96.9
19	3	1.8	1.9	98.8
20	2	1.2	1.2	100.0
Total	162	98.8	100	
Missing	2	1.2		
Total	164	100		

IPQ-R: Subscale 'Consequences' Frequency Table

	Frequency	%	Valid %	Cumulative %
6	6	3.7	3.7	3.7
7	3	1.8	1.8	5.5
8	6	3.7	3.7	9.1
9	8	4.9	4.9	14.0
10	10	6.1	6.1	20.1
11	12	7.3	7.3	27.4
12	15	9.1	9.1	36.6
13	10	6.1	6.1	42.7
14	23	14.0	14.0	56.7
15	10	6.1	6.1	62.8
16	1	0.6	0.6	63.4
16	20	12.2	12.2	75.6
17	1	0.6	0.6	76.2
17	10	6.1	6.1	82.3
18	11	6.7	6.7	89.0
19	4	2.4	2.4	91.5
20	4	2.4	2.4	93.9
21	3	1.8	1.8	95.7
22	2	1.2	1.2	97.0
23	2	1.2	1.2	98.2
25	1	0.6	0.6	98.8
26	1	0.6	0.6	99.4
29	1	0.6	0.6	100.0
Total	154	100.0	100.0	

IPQ-R: Subscale 'Personal Control' Frequency Table

	Frequency	%	Valid %	Cumulative %
6	1	0.6	0.6	0.6
7	1	0.6	0.6	1.2
9	1	0.6	0.6	1.8
10	6	3.7	3.7	5.5
12	4	2.4	2.4	7.9
13	7	4.3	4.3	12.2
14	10	6.1	6.1	18.3
15	9	5.5	5.5	23.8
16	24	14.6	14.6	38.4
17	17	10.4	10.4	48.8
18	26	15.9	15.9	64.6
19	14	8.5	8.5	73.2
20	1	0.6	0.6	73.8
20	12	7.3	7.3	81.1
21	7	4.4	4.4	85.4
22	9	5.5	5.5	90.9
23	7	4.3	4.3	95.1
24	2	1.2	1.2	96.3
25	2	1.2	1.2	97.6
25	1	0.6	0.6	98.2
26	1	0.6	0.6	98.8
27	1	0.6	0.6	99.4
30	1	0.6	0.6	100.0
Total	164	100.0	100.0	

IPQ-R: Subscale ‘Treatment Control’ Frequency Table

	Frequency	%	Valid %	Cumulative %
9	2	1.2	1.2	1.2
10	1	.6	.6	1.9
11	2	1.2	1.2	3.1
13	7	4.3	4.3	7.4
14	4	2.4	2.5	9.9
15	15	9.1	9.3	19.1
16	17	10.4	10.5	29.9
17	20	12.2	12.3	42.0
18	13	7.9	8.0	50.0
19	13	7.9	8.0	58.0
20	29	17.7	17.9	75.9
21	13	7.9	8.0	84.0
22	10	6.1	6.2	90.1
23	6	3.7	3.7	93.8
24	77	4.3	4.3	98.1
25	43	1.8	1.9	100.0
Total	162	98.	100.0	
Missing	1	.6		
Total	164	100.0		

IPQ-R: Subscale 'Illness Coherence' Frequency Table

	Frequency	%	Valid %	Cumulative %
5	5	3.0	3.1	3.1
7	1	0.6	0.6	3.7
8	4	2.4	2.5	6.1
9	8	4.9	4.9	11.0
10	15	9.1	9.2	20.2
11	9	5.5	5.5	25.8
12	11	6.7	6.7	32.5
13	1	0.6	0.6	33.1
13	6	3.7	3.7	36.8
14	10	6.1	6.1	42.9
15	14	8.5	8.6	51.5
16	13	7.9	8.0	59.5
16	1	0.6	0.6	60.1
17	14	8.5	8.6	68.7
18	12	7.3	7.4	76.1
19	6	3.7	3.7	79.8
20	9	5.5	5.5	85.3
21	4	2.4	2.5	87.7
21	1	0.6	0.6	88.3
22	4	2.4	2.5	90.8
23	1	0.6	0.6	91.4
24	1	0.6	0.6	92.0
24	6	3.7	3.7	95.7
25	7	4.3	4.3	100.0
Total	163	99.4	100.0	
Missing	1	0.6		
Total	164	176	100	

IPQ-R: Subscale 'Emotional Representations' Frequency Table

	Frequency	%	Valid %	Cumulative %
6	5	3.0	3.1	3.1
7	3	1.8	1.9	4.9
8	1	0.6	0.6	5.6
9	7	4.3	4.3	9.9
10	7	4.3	4.3	14.2
11	2	1.2	1.2	15.4
12	11	6.7	6.8	22.2
13	12	7.3	7.4	29.6
14	14	8.5	8.6	38.3
15	5	3.0	3.1	41.4
16	5	3.0	3.1	44.4
17	1	0.6	0.6	45.1
17	9	5.5	5.6	50.6
18	9	5.5	5.6	56.2
19	9	5.5	5.6	61.7
19	2	1.2	1.2	63.0
20	7	4.3	4.3	67.3
21	9	5.5	5.6	72.8
22	12	7.3	7.4	80.2
23	6	3.7	3.7	84.0
24	9	5.5	5.6	89.5
25	3	1.8	1.9	91.4
26	7	0.6	4.3	95.7
27	3	1.8	1.9	97.5
28	21	0.6	0.6	98.1
29	3	1.8	1.9	100.0
Total	162	98.8	100.0	
Missing	2	1.2		
Total	164	100.0	100.0	

'Body Shape' (BSQ16A) Frequency Table

	Frequency	%	Valid %	Cumulative %
16	13	7.9	7.9	7.9
18	8	4.9	4.9	12.8
19	1	0.6	0.6	13.4
20	5	3.0	3.0	16.5
20	1	0.6	0.6	17.1
21	2	1.2	1.2	18.3
22	3	1.8	1.8	20.1
24	5	3.0	3.0	23.2
25	2	1.2	1.2	24.4
26	1	0.6	0.6	25.0
26	4	1.2	1.2	27.4
27	1	0.6	0.6	28.0
28	2	1.2	1.2	29.3
29	6	3.7	3.7	32.9
30	8	4.9	4.9	37.8
31	1	0.6	0.6	38.4
31	4	2.4	2.4	40.9
32	5	3.0	3.0	43.9
33	4	2.4	2.4	46.3
33	1	0.6	0.6	47.0
34	4	2.4	2.4	49.4
35	3	1.8	1.8	51.2
36	3	1.8	1.8	53.0
37	6	3.7	3.7	56.7
38	2	1.2	1.2	57.9
39	3	1.8	1.8	59.8
40	1	0.6	0.6	60.4
41	3	1.8	1.8	62.2
42	1	0.6	0.6	62.8
43	1	0.6	0.6	63.4
43	2	1.2	1.2	64.6
44	1	0.6	0.6	65.2
44	2	1.2	1.2	66.5
46	1	0.6	0.6	67.1
47	2	1.2	1.2	68.3
48	3	1.8	1.8	70.1
49	6	3.7	3.7	73.9
50	1	0.6	0.6	74.4
51	2	1.2	1.2	75.6
53	1	0.6	0.6	76.2
54	1	0.6	0.6	76.8
55	4	2.4	2.4	79.3

56	3	1.8	1.8	81.1
57	1	0.6	0.6	81.7
58	3	1.8	1.8	83.5
59	1	0.6	0.6	84.1
61	3	1.8	1.8	86.0
62	2	1.2	1.2	87.2
63	2	1.2	1.2	88.4
64	3	1.8	1.8	90.2
66	2	1.2	1.2	91.5
66	1	0.6	0.6	92.1
68	1	0.6	0.6	92.7
69	1	0.6	0.6	93.3
70	2	1.2	1.2	94.5
72	1	0.6	0.6	95.1
75	1	0.6	0.6	95.7
76	1	0.6	0.6	96.3
77	3	1.8	1.8	98.2
78	1	0.6	0.6	98.8
79	1	0.6	0.6	99.4
80	1	0.6	0.6	100.0
Total	164	100.0	100.0	

'Risk Factor' Knowledge Frequency Table

	Frequency	%	Valid %	Cumulative %
5	3	1.8	1.9	1.9
7	2	1.2	1.2	3.1
8	10	6.1	6.2	9.3
8	1	0.6	0.6	9.9
9	7	4.3	4.3	14.2
9	1	0.6	0.6	14.8
10	7	4.3	4.3	19.1
11	13	7.9	8.0	27.2
12	1	0.6	0.6	27.8
12	16	9.8	9.9	37.7
13	1	0.6	0.6	38.3
13	1	0.6	0.6	38.9
13	1	0.6	0.6	39.5
13	1	0.6	0.6	40.1
13	27	16.5	16.7	56.8
14	1	0.6	0.6	57.4
14	26	15.9	16.1	73.5
15	18	11.0	11.1	84.6
16	2	1.2	1.2	85.8
16	16	9.8	9.9	95.7
17	4	2.4	2.5	98.1
18	3	1.8	1.9	100.0
Total	162	98.8	100.0	
Missing	2	1.2		
Total	164	100		

'Perceived Risk' Frequency Table

	Frequency	%	Valid %	Cumulative %
Less at risk	26	15.9	16.1	16.1
At similar risk	102	62.2	63.4	79.5
More at risk than others around you	33	20.1	20.5	100.0
Total	161	98.2	100.0	
Missing	3	1.8		
Total	164	100.0	100.0	

'Symptom Knowledge' Frequency Table

	Frequency	%	Valid %	Cumulative %
3	1	0.6	0.6	0.6
4	1	0.6	0.6	1.2
5	5	3.0	3.0	4.3
6	5	3.0	3.0	7.3
7	4	2.4	2.4	9.8
7	1	0.6	0.6	10.4
8	11	6.7	6.7	17.1
9	17	10.4	10.4	27.4
10	1	0.6	0.6	28.0
10	22	13.4	13.4	41.5
11	18	11.0	11.0	52.4
12	34	20.7	20.2	73.2
13	23	14.0	14.0	87.2
14	15	9.1	9.1	96.3
15	5	3.0	3.0	99.4
17	1	0.6	0.6	100.0
Total	164	100.0	100.0	

'Waist-hip-ratio' Frequency Table

	Frequency	%	Valid %	Cumulative %
0.45	1	0.6	0.7	0.7
0.50	1	0.6	0.7	1.3
0.54	1	0.6	0.7	2.0
0.68	1	0.6	0.7	2.7
0.68	1	0.6	0.7	3.4
0.73	1	0.6	0.7	4.0
0.73	1	0.6	0.7	4.7
0.74	1	0.6	0.7	5.4
0.74	1	0.6	0.7	6.0
0.74	1	0.6	0.7	6.7
0.75	1	0.6	0.7	7.4
0.75	1	0.6	0.7	8.1
0.75	1	0.6	0.7	8.7
0.75	1	0.6	0.7	9.4
0.75	1	0.6	0.7	10.1
0.76	1	0.6	0.7	10.7
0.76	1	0.6	0.7	11.4
0.77	1	0.6	0.7	12.1
0.77	2	1.2	1.7	13.4
0.77	1	0.6	0.7	14.1
0.78	1	0.6	0.7	14.8

0.78	1	0.6	0.7	15.4
0.78	1	0.6	0.7	16.1
0.79	1	0.6	0.7	16.8
0.79	1	0.6	0.7	17.4
0.79	1	0.6	0.7	18.1
0.79	1	0.6	0.7	18.8
0.79	1	0.6	0.7	19.5
0.79	1	0.6	0.7	20.1
0.80	1	0.6	0.7	20.8
0.80	1	0.6	0.7	21.5
0.80	1	0.6	0.7	22.8
0.80	2	1.2	1.3	21.5
0.80	1	0.6	0.7	22.8
0.80	1	0.6	0.7	23.5
0.81	1	0.6	0.7	24.2
0.81	3	1.8	2.0	24.8
0.81	1	0.6	0.7	26.8
0.81	1	0.6	0.7	27.5
0.81	1	0.6	0.7	28.2
0.82	1	0.6	0.7	28.9
0.82	1	0.6	0.7	29.5
0.82	1	0.6	0.7	30.2
0.82	1	0.6	0.7	30.9
0.82	1	0.6	0.7	31.5
0.82	1	0.6	0.7	32.3
0.82	1	0.6	0.7	32.9
0.82	1	0.6	0.7	33.6
0.83	1	0.6	0.7	34.2
0.83	1	0.6	0.7	34.9
0.83	1	0.6	0.7	35.6
0.83	1	0.6	0.7	36.2
0.83	1	0.6	0.7	36.9
0.83	1	0.6	0.7	37.9
0.84	1	0.6	0.7	38.3
0.84	1	0.6	0.7	38.9
0.84	2	1.2	1.3	39.6
0.84	1	0.6	0.7	40.3
0.84	2	1.2	1.3	41.6
0.84	1	0.6	0.7	42.3
0.84	1	0.6	0.7	43.6
0.84	1	0.6	0.7	44.3
0.84	1	0.6	0.7	45.0
0.84	1	0.6	0.7	45.6
0.84	1	0.6	0.7	46.3

0.84	1	0.6	0.7	47.0
0.85	1	0.6	0.7	47.7
0.85	1	0.6	0.7	48.3
0.85	1	0.6	0.7	49.0
0.85	1	0.6	0.7	49.7
0.85	1	0.6	0.7	50.3
0.85	1	0.6	0.7	51.0
0.85	1	0.6	0.7	51.7
0.85	1	0.6	0.7	52.3
0.86	1	0.6	0.	53.0
0.86	1	0.6	0.6	53.7
0.86	2	1.3	1.3	54.4
0.86	1	0.6	0.7	55.0
0.86	1	0.6	0.7	56.4
0.86	1	0.6	0.7	57.0
0.86	1	0.6	0.7	57.7
0.86	1	0.6	0.7	58.4
0.86	1	0.6	0.7	59.1
0.86	1	0.6	0.7	60.4
0.86	1	0.6	0.7	61.1
0.86	1	0.6	0.7	61.7
0.86	1	0.6	0.7	62.4
0.87	1	0.6	0.7	63.1
0.87	1	0.6	0.7	63.8
0.87	2	1.2	1.3	64.4
0.87	1	0.6	0.6	65.8
0.87	1	0.6	0.7	66.4
0.87	1	0.6	0.7	67.1
0.87	1	0.6	0.7	67.8
0.87	1	0.6	0.7	68.5
0.87	1	0.6	0.7	69.1
0.87	2	1.2	1.3	69.8
0.87	1	0.6	0.7	71.1
0.87	1	0.6	0.7	71.8
0.88	1	0.6	0.7	72.5
0.88	2	1.2	1.3	73.2
0.88	1	0.6	0.7	74.5
0.89	1	0.6	0.7	75.2
0.89	1	0.6	0.7	75.8
0.89	1	0.6	0.7	76.5
0.89	2	1.2	1.3	77.2
0.89	1	0.6	0.7	78.5
0.89	1	0.6	0.7	79.2
0.89	1	0.6	0.7	79.9

0.89	1	0.6	0.7	80.5
0.89	2	1.2	1.3	81.2
0.90	1	0.6	0.7	83.2
0.90	1	0.6	0.7	83.9
0.90	1	0.6	0.7	84.5
0.90	1	0.6	0.7	85.2
0.91	1	0.6	0.7	85.1
0.91	1	0.6	0.7	86.6
0.91	1	0.6	0.7	87.2
0.91	1	0.6	0.7	87.9
0.92	1	0.6	0.7	88.6
0.92	1	0.6	0.7	89.3
0.93	1	0.6	0.7	89.9
0.93	1	0.6	0.7	90.6
0.93	1	0.6	0.7	91.3
0.94	1	0.6	0.7	91.9
0.94	1	0.6	0.7	92.6
0.95	2	0.6	0.7	93.3
0.95	1	0.6	0.7	94.6
0.98	1	0.6	0.7	95.3
0.99	1	0.6	0.7	96.0
0.99	1	0.6	0.7	96.6
1.00	2	1.3	1.3	98.0
1.06	1	0.6	0.7	98.7
1.48	1	0.6	0.	99.3
1.58	1	0.6	0.7	100.0
Total	149	90.3	100.0	
Missing	15	16	9.1	
Total	164	176	100.0	

BMI Frequency Table

	Frequency	%	Valid %	Cumulative %
19	1	0.6	0.6	0.6
20	1	0.6	0.6	1.3
21	2	1.2	1.3	2.6
21	1	0.6	0.6	3.2
21	3	1.8	1.9	5.1
22	1	0.6	0.6	5.8
22	1	0.6	0.6	6.4
22	2	1.2	1.3	7.7
23	1	0.6	0.6	8.3
23	2	1.2	1.3	9.6
23	1	0.6	0.6	10.3
23	1	0.6	0.6	10.9
23	3	0.6	1.8	11.5
24	2	1.2	1.3	12.8
24	2	1.2	1.3	14.1
24	2	1.2	1.3	15.4
24	3	1.8	1.9	17.3
24	1	0.6	0.6	17.9
24	1	0.6	0.6	18.6
24	2	1.2	1.3	19.9
25	1	0.6	0.6	20.5
25	1	0.6	0.6	21.2
25	1	0.6	0.6	21.8
25	2	1.2	1.3	23.1
26	3	1.8	1.9	25.0
26	1	0.6	0.6	25.6
26	1	0.6	0.6	26.3
26	1	0.6	0.6	26.9
26	1	0.6	0.6	27.6
26	1	0.6	1.3	28.2
26	1	0.6	0.6	28.8
26	1	0.6	0.6	29.5
26	1	0.6	0.6	30.1
27	1	0.6	0.6	30.8
27	1	0.6	0.6	31.4
27	1	0.6	0.6	32.1
27	3	1.8	1.9	34.0
27	1	0.6	0.6	34.6
27	1	0.6	0.6	35.9
27	1	0.6	0.6	36.5
28	2	1.2	1.3	37.8
28	1	0.6	0.6	38.5

28	1	0.6	0.6	39.1
28	1	0.6	0.6	39.7
28	1	0.6	0.6	40.4
28	1	0.6	0.6	41.0
29	1	0.6	0.6	41.7
29	1	1.2	1.3	42.3
29	2	0.6	0.6	43.6
30	1	0.6	0.6	44.2
30	1	0.6	0.6	44.9
30	3	1.8	1.9	46.8
30	6	3.7	3.8	50.6
30	1	0.6	0.6	51.3
30	2	1.2	1.3	52.6
30	1	0.6	0.6	53.2
31	1	0.6	0.6	53.8
31	3	1.8	1.9	55.8
31	1	0.6	0.6	56.4
31	1	0.6	0.6	57.1
31	1	0.6	0.6	57.7
32	3	1.8	1.9	59.6
32	2	1.2	1.2	60.9
32	2	1.2	1.2	62.2
32	4	2.4	2.5	64.7
32	3	1.8	1.9	66.7
32	1	0.6	0.6	67.3
33	1	0.6	0.6	67.9
33	1	0.6	0.6	68.6
33	2	0.6	0.6	69.9
34	1	0.6	0.6	70.5
34	1	0.6	0.6	71.2
35	1	0.6	0.6	71.8
35	1	0.6	0.6	72.4
35	1	0.6	0.6	73.1
35	2	1.2	1.3	74.4
36	2	1.2	1.3	75.6
36	1	0.6	0.6	76.3
36	2	1.2	1.3	77.6
36	1	0.6	0.6	78.2
37	1	0.6	0.6	78.8
37	3	1.8	1.9	80.8
37	1	0.6	0.6	81.4
38	1	0.6	0.6	82.1
39	2	1.2	1.3	83.3
39	1	0.6	0.6	84.0

40	1	0.6	0.6	84.6
40	1	0.6	0.6	85.3
40	1	0.6	0.6	85.9
41	1	0.6	0.6	86.5
42	2	1.2	1.3	87.8
42	1	0.6	0.6	88.5
42	1	0.6	0.6	89.1
43	1	0.6	0.6	89.7
43	1	0.6	0.6	90.4
43	1	0.6	0.6	91.0
44	1	0.6	0.6	91.7
45	1	0.6	0.6	92.3
46	1	0.6	0.6	92.9
46	1	0.6	0.6	93.6
48	1	0.6	0.6	94.2
48	1	0.6	0.6	94.9
50	1	0.6	0.6	95.5
53	1	0.6	0.6	96.2
54	2	1.2	1.3	97.4
60	1	0.6	0.6	98.1
61	1	0.6	0.6	98.7
62	1	0.6	0.6	99.4
69	1	0.6	0.6	100.0
Total	156	95.1	100	
Missing	8	4.9		
Total	154	100.0	100	

Ethnicity Categories Frequency Table

	Frequency	%	Valid %	Cumulative %
White European	131	79.9	82.4	82.4
Black African	11	6.7	6.9	89.3
South Asian/Asian British	17	10.4	10.7	100.0
Other		97	100	
Total	159	3.0		
Missing	5	100		
Total	131	79.9	82.4	

Years residing in UK Frequency Table

	Frequency	%	Valid %	Cumulative %
1-5 yrs	1	0.6	0.6	0.6
5-10 yrs	2	1.2	1.2	1.8
10-20 years	4	2.4	2.4	4.3
20+ years	17	10.4	10.4	14.6
British Born	140	85.4	85.4	100.0
Total	164	100.0	100.0	

Generations of English Speaking Frequency Table

	Frequency	%	Valid %	Cumulative %
0	4	2.4	2.4	2.4
1	12	7.3	7.3	9.8
2	15	9.1	9.1	18.9
3	5	3.0	3.0	22.0
4	128	78.0	78.0	100.0
Total	164	100.0	100.0	

HHQ: Subscale 'Previous Health Behaviours' Frequency Table

	Frequency	%	Valid %	Cumulative %
1	115	70.1	70.6	70.6
2	48	29.3	29.4	100.0
Total	163	99.4	100.0	
Missing	1	0.6		
Total	164	100.0		

HHQ: Subscale 'Health Promoting Behaviours' Frequency Table

	Frequency	%	Valid %	Cumulative %
1	84	51.2	51.5	51.5
2	79	48.2	48.5	100.0
Total	163	99.4	100.0	
Missing	1	0.6		
Total	164	100.0		

HHQ: Subscale 'Health Harming Behaviours' Frequency Table Frequency Table

	Frequency	%	Valid %	Cumulative %
2	6	3.7	3.8	3.8
3	2	1.2	1.3	5.1
4	8	4.9	5.1	10.1
5	9	5.5	5.7	15.8
6	29	17.7	18.4	34.2
7	25	15.2	15.8	50.0
8	38	23.2	24.1	74.1
9	18	11.0	11.4	85.4
10	23	14.0	14.6	100.0
Total	158	96.3	100.0	
Missing	6	3.7		
Total	164	100.0		

HHQ: Subscale 'Perceived Body Weight' Frequency Table

	Frequency	%	Valid %	Cumulative %
2	2	1.2	1.2	1.2
3	2	1.2	1.2	2.5
4	18	11.0	11.0	13.5
5	18	11.0	11.0	24.5
6	27	16.5	16.6	41.1
7	23	14.0	14.1	55.2
8	39	23.8	23.9	79.1
9	18	11.0	11.0	90.2
10	16	9.8	9.8	100.0
Total	163	99.4	100.0	
Missing	1	0.6		
Total	164	100.0		

HHQ: Subscale Present ‘Comorbidities’ Frequency Table

	Frequency	%	Valid %	Cumulative %
2	95	57.9	59	59
3	16	9.8	9.9	68.9
4	10	6.1	6.2	75.2
5	7	4.3	4.3	79.5
6	23	14	14.3	93.8
7	4	2.4	2.5	96.3
8	2	1.2	1.2	97.5
9	1	0.6	0.6	98.1
10	3	1.8	1.9	100.0
Total	161	98.2	100.0	
Missing	3	1.8		
Total	164	100.0		

Social Capital: Subscale ‘Neighbourhood Belonging’ Frequency Table

	Frequency	%	Valid %	Cumulative %
-4	4	2.4	2.4	2.4
-2	3	1.8	1.8	4.3
0	15	9.1	9.1	13.4
1	1	0.6	0.6	14
1	1	0.6	0.6	14.6
2	35	21.3	21.3	36.0
4	1	0.6	0.6	36.6
4	45	27.4	27.4	64.0
6	59	36.0	36.0	100.0
Total	164	100.0	100.0	

Social Capital: Subscale ‘Neighbourhood Crime’ Frequency Table

	Frequency	%	Valid %	Cumulative %
-1	19	11.6	11.6	11.6
0	142	86.6	86.6	98.2
1	3	1.8	1.8	100.0
Total	164	100.0	100.0	

Social *Capital: Subscale ‘Community Activity’ Frequency Table*

	Frequency	%	Valid %	Cumulative %
1	2	1.2	1.2	1.2
2	2	1.2	1.2	2.4
3	3	1.8	1.8	4.3
4	2	1.2	1.2	5.5
5	13	7.9	7.9	13.4
Total	3	1.8	1.8	15.2
Missing	1	0.6	0.6	15.9
Total	31	18.9	18.9	34.8

Social Capital: Subscale Social Support Frequency Table

	Frequency	%	Valid %	Cumulative %
-5	2	1.2	1.2	1.2
-4	2	1.2	1.2	2.4
-2	3	1.8	1.8	4.3
-1	2	1.2	1.2	5.5
No close contact with friends/family	13	7.9	7.9	13.4
Close contact with relatives or friends only	3	1.8	1.8	15.2
1	1	0.6	0.6	15.9
2	31	18.9	18.9	34.8
3	7	4.3	4.3	39
3	1	0.6	0.6	39.6
4	39	23.8	23.8	63.4
5	9	5.5	5.5	68.9
6	51	31.1	31.1	100.0
Total	164	100.0	100.0	

Social Capital: Subscale Number of Contacts Frequency Table

	Frequency	%	Valid %	Cumulative %
0	5	3.0	3.0	3.0
0-2 contacts	8	4.9	4.9	7.9
2-3 contacts	17	10.4	10.4	18.3
4 or more contacts	98	59.8	59.8	78.0
4	24	14.6	14.6	92.7
5	9	5.5	5.5	98.2
5	1	0.6	0.6	98.8
6	1	0.6	0.6	99.4
9	1	0.6	0.6	100.0
Total	164	100.0	100.0	

APPENDIX M

Chapter 5: Aarhus statements checklist & descriptive statistics

The Aarhus checklist (Weller et al., 2012)

DEFINITIONS OF TIME POINTS AND INTERVALS	**Yes/No**	
1. For studies requiring the measurement of an interval, are the beginning and end points of this interval clearly defined?	Yes	pg. 129; 154-157
2. For all time points and intervals described, are there precise, transparent and repeatable definitions, and is the complexity of time points such as the date of first symptom and date of first presentation addressed?		pg. 129-130; 154-157
For studies that require an estimate of the date of first symptom:		
3. Do the researchers refer to a theoretical framework underpinning definition of this time point?	Yes	Chp 2 & pg. 120; pg.128
4. Is there a discussion of the different biases influencing measurement of this time point?	Yes	Chp 2 & pg. 120; 150
For studies that require measurement of a date of first presentation to healthcare:		
5. Do the researchers discuss the complexity of the date of first presentation?	Yes	pg. 128-130; 154-157
For studies that require measurement of a date of referral:		
6. Do the researchers discuss the nature of the referral and provide adequate detail – for example, whether it was for investigation or consultation by a colleague in secondary care?	Yes	pg. 16-18; 133; 155-157; 174
For studies that require measurement of the date of diagnosis:		
7. Do the researchers use an existing hierarchical rationale for the date of diagnosis measurement?	N/A	
8. Is the healthcare context in which the study is based fully described?	N/A	
9. Do the questions on time points and/or intervals clearly derive from stated definitions?	N/A	
10. Do researchers acknowledge the need for theoretical validation and make reference to the theoretical framework(s) underpinning measurement and analysis of the time points?	N/A	
11. Has a validated instrument been used?	N/A	
12. Have the researchers included a copy of their instrument?	N/A	
13. Is there some discussion of how reliability and validity (trustworthiness) has been established?	N/A	
14. Do researchers acknowledge the need for theoretical validation and make reference to the theoretical framework(s)	N/A	

underpinning measurement and analysis of the time points?

15. Is there discussion of the different biases influencing measurement of the time points, such as how and when the question is asked and who is being asked?	N/A
16. Is the timing of the interview in relation to the date of diagnosis provided?	N/A
17. Is there any triangulation of self-reported data with other data sources such as case notes?	N/A
18. Is data analysis described in full including how and why data are categorised, how missing and incomplete data are managed, and how outliers at both ends of the spectrum are accounted for?	N/A
<u>For studies using primary case-note audit and database analysis:</u>	
19. Case-note analysis: is there a clear and precise description of how case-note data were used to ascertain time points with an acknowledgment of limitations of such data?	N/A
20. For database analysis: is there a thorough description of the database chosen including sampling coverage and completeness of information?	N/A

Descriptive Statistics: Exploring data outliers

	N	Min.	Max.	Mean	Std. Deviation
Mood					
Anxiety	163	0	21	8.45	5.057
Depression	163	0	20	4.92	3.843
Illness Perception Questionnaire					
Timeline	164	8	26	15.16	3.170
Timecycle	162	4	20	11.54	3.273
Consequences	164	6	29	14.03	4.161
Personal Control	164	6	30	17.53	3.776
Treatment Control	162	9	25	18.33	3.272
Illness Coherence	163	5	25	15.27	4.906
Emotional Representation	162	6	29	17.25	5.731
Body Shape Questionnaire	164	16	80	39.09	17.408
Risk Factors [Knowledge]	162	5	18	12.75	2.705
Symptoms [Knowledge]	164	3	17	10.82	2.547
Health History Questionnaire					
Preventative Health Behav.	163	1	2	1.29	.457
Health Promoting Behav.	163	1	2	1.48	.501
Health Harming Behav.	158	2	10	7.22	2.001
Perceived Body Weight	163	2	10	6.93	1.920
Comorbidities	161	2	10	3.32	1.970
Social Capital					
Neighbourhood Belonging	164	-4	6	3.58	2.438
Neighbourhood Crime	164	-1	1	-.10	.354
Community Activity	163	1	5	3.58	1.583
Social Support	164	-5	6	3.48	2.467
Number of contacts	164	0	9	3.03	1.119

Comparing ‘markedly extended time’ to help-seeking (i.e. more than 1 month) and ‘timely' help-seeking (within 2 weeks)

	markedly extended time' help-seekers (>1 month)					*'timely' help-seekers (within 2 weeks)*				
Variable(s)	N (Total N = 50)	%	Mean	Std. Deviation	Range	N (Total N = 83)	%	Mean	Std. Deviation	Range
Age	50		59.08	8.77	38 - 79	83		59.22	9.83	41 - 85
WaistHipR	43		0.85	0.14	.50 – 1.50	76		0.85	0.12	.45 – 1.48
BMI	49		31.12	8.52	19 - 62	78		32.99	9.4	47 - 69
Obesity	49					78				
Non-obese	24	49.00%				27	34.60%			
Obese	25	51.00%				51	65.40%			
Education	46					80				
Less than compulsory	6	13.00%				5	6.30%			
Compulsory	24	52.20%				57	71.80%			
Above compulsory	16	34.80%				18	18.80%			
Postgraduate	0	0.00%				3	3.80%			
Marital Status	47					82				
Single	10	21.30%				14	8.50%			
Married	24	51.10%				44	53.70%			
Widowed	5	10.60%				13	15.90%			
Divorced/Separated	7	17.00%				11	12.50%			
Deprivation	48					82				
None	30	62.50%				12	65.90%			
Minimal	12	25.00%				18	22.00%			
Slight	2	4.32%				7	8.50%			
Moderate	4	8.30%				3	3.70%			
Ethnicities	46					82				
White European	32	69.60%				73	89.00%			
Black African/Other	5	10.90%				3	3.70%			
South Asian/Other Asian	9	19.60%				6	7.30%			

Variable(s)	N (Total N = 50)	%	Mean	Std. Deviation	Range	N (Total N = 50)	%	Mean	Std. Deviation	Range
Years in UK	50					83				
1-5 yrs in UK	1	2.00%				1	1.20%			
10-20 yrs in UK	4	8.00%				0	0.00%			
20+ yrs in UK	7	14.00%				8	9.60%			
British Born	38	76.00%				74	89.20%			
Religion	46					82				
Catholic/Christian	28	60.80%				57	69.50%			
Muslim	2	4.30%				1	1.20%			
Hindu	1	2.30%				1	1.20%			
Sikh	4	8.70%				4	4.90%			
None	9	19.60%				15	18.30%			
Other	2	4.30%				4	4.90%			
Generations English in Family	50					68				
Non-English speaking	1	2.00%				2	2.40%			
First generation	6	12.00%				5	6.00%			
Second generation	10	20.00%				8	9.60%			
All of family English speaking	33	66.00%				68	81.90%			
Clinical Outcomes	50					83				
Endometrial cancer	2	4.00%				5	6.00%			
Cervical pre-cancer	0	0.00%				1	1.20%			
Monitoring ovarian cyst	3	6.00%				5	6.00%			
Hysterectomy (due to cancer risk)	7	14.00%				2	2.40%			
Discharged after investigation/benign biopsy	24	48.00%				42	50.60%			
Benign Polyp(s)/ Fibroid(s)	6	12.40%				13	15.70%			
Discharged due to non-attendance at follow-up	1	2.00%				3	3.60%			

Variable(s)	N (Total N = 50)	%	Mean	Std. Deviation	Range	N (Total N = 50)	%	Mean	Std. Deviation	Range
Other Cause (e.g. urinary issue, womb prolapse, atrophic vaginosis, problem with coil)	6	12.00%				9	10.80%			
Incorrect referral from GP	1	2.00%				3	1.20%			
Mood						82				
Anxiety	50		8.44	4.66	0 -21	82		8.82	4.75	0 - 20
Depression	50		4.87	3.66	0 - 13	82		5.06	3.57	0 - 14
Illness Perception						83				
Timeline	50		15.22	3.16	8 - 24	83		15.03	2.69	9 - 23
Timecycle	48		11.53	3.11	4 - 17	83		11.38	3.16	4 - 19
Consequences	50		15.25	3.76	9 - 26	83		13.77	3.94	6 - 29
Personal Control	50		17.39	3.71	10 - 27	83		17.32	3.82	6 - 26
Treatment Control	48		18.19	3.19	10 - 24	83		18.14	2.97	9 - 24
Illness Coherence	49		15.76	5.00	5 - 24	83		14.5	5.02	5 - 25
Emotional Representation	49		17.33	5.57	6 - 26	83		17.3	5.98	6 - 29
Body Shape	50		38.76	17.57	16 - 80	83		39.63	17.57	16 - 80
Risk factor knowledge	49		13.27	2.48	5 - 18	83		12.41	2.48	5 - 18
Personal risk	50					81				
Less at risk	8	16.00%				14	17.30%			
At similar risk	33	66.00%				50	61.70%			
More at risk than others	9	18.00%				17	21.00%			
Symptom Knowledge	50		10.99	2.45	5 - 15	83				3 - 17
Health History										
Preventative Health Behav.	49		1.96	0.20	1 - 2	83				1 - 2
Health Promoting Behav.	49		2	0.00	2 - 2	81				1 - 2
Health Harming Behav.	48		7.25	2.02	2 - 10	82				2 - 10
Perceived Body Weight	50		6.58	1.70	3 - 10	83				2 - 10
Comorbidities	48		3.21	1.95	2 - 10	83				2 - 10
Social Capital	50					83				

Variable(s)	N (Total N = 50)	%	Mean	Std. Deviation	Range	N (Total N = 50)	%	Mean	Std. Deviation	Range
Neighbourhood Belonging	50		3.87	1.95	- 4 - 6	83				-1 - 6
Neighbourhood Crime	50		-0.06	2.57	-1 - 1	83				-1 - 1
Community Activity	50		3.22	0.31	1 - 5	83				1 - 5
Social Support	50		3.81	1.70	-4 - 6	83				-5 - 6
Presence of concern	22					28				
Concern before help-seeking	20					5				
No Concern before help-seeking	2					23				
Method of help-seeking	50					73				
Emergency (A&E)	2	4.00%				3	3.60%			
GP Surgery	30	60.00%				73	88.00%			
Other: Screening/comorbidity appointment	18	36.00%				7	8.40%			
Valid N (listwise)	50					50				

Chi-square statistic of difference between markedly delayed and timely help-seeking group and 'Generations of English Speaking in Family'

Crosstabs table: Generations of English Speaking in Family across markedly delayed & timely help-seeking group

		Generations of English Speaking in Family amongst timely help-seeking grp.					
		0	1	2	3	4	Total
Generations of English Speaking in Family amongst markedly delayed grp.	No English speakers	0	0	0	0	1	1
	1st generation	0	1	0	2	3	6
	2 generations	0	2	2	0	4	8
	3 generations	0	0	0	0	2	2
	All of family English speaking	1	2	0	0	30	33
Total		1	5	2	2	40	50

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	30.777[a]	16	.014
Likelihood Ratio	21.755	16	.151
Linear-by-Linear Association	2.618	1	.106
N of Valid Cases	50		

a. 23 cells (92.0%) have expected count less than 5. The minimum expected count is .02.

Descriptive statistics on measures for obese and non-obese participants

Descriptive Statistics: Measures for obese and non-obese participants

		N	Mean	Std. Deviation	Min.	Max.
Anxiety	Non-obese	68	7.91	5.182	0	20
	Obese	87	8.91	4.856	0	21
	Total	155	8.47	5.010	0	21
Depression	Non-obese	68	4.28	4.042	0	20
	Obese	87	5.44	3.572	0	13
	Total	155	4.93	3.816	0	20
Timeline	Non-obese	68	15.17	2.931	8	24
	Obese	88	15.02	3.285	8	26
	Total	156	15.08	3.127	8	26
Timecycle	Non-obese	67	10.79	3.518	4	20
	Obese	87	12.09	2.940	6	19
	Total	154	11.52	3.259	4	20
Consequences	Non-obese	68	13.10	4.056	6	26
	Obese	88	14.74	4.161	6	29
	Total	156	14.02	4.182	6	29
Personal Control	Non-obese	68	17.38	3.681	10	30
	Obese	88	17.73	3.788	6	27
	Total	156	17.58	3.734	6	30
Treatment Control	Non-obese	67	17.87	3.576	9	25
	Obese	87	18.57	3.002	9	24
	Total	154	18.27	3.272	9	25
Illness Coherence	Non-obese	67	15.81	5.065	5	25
	Obese-	88	15.07	4.793	5	25
	Total	155	15.39	4.910	5	25
Emotional Representation	Non-obese	66	16.13	5.756	6	28
	Obese	88	17.95	5.504	6	29
	Total	154	17.17	5.667	6	29
Body Shape	Non-obese	68	34.69	16.771	16	79
	Obese-	88	42.88	17.024	16	80
	Total	156	39.31	17.345	16	80
Risk Factors [Knowledge]	Non-obese	68	12.94	2.493	5	16
	Obese	87	12.58	2.889	5	18
	Total	155	12.74	2.720	5	18
Symptoms [Knowledge]	Non-obese	68	10.99	2.440	5	17
	Obese	88	10.77	2.589	3	15
	Total	156	10.87	2.520	3	17
Preventative health Behav.	Non-obese	68	1.37	.486	1	2

	Obese	87	1.25	.437	1	2
	Total	155	1.30	.461	1	2
Health Promoting Behav.	Non-obese	68	1.57	.498	1	2
	Obese	87	1.43	.497	1	2
	Total	155	1.49	.502	1	2
Health Harming Behav.	Non-obese	66	6.94	1.937	2	10
	Obese	84	7.48	2.021	2	10
	Total	150	7.24	1.996	2	10
Perceived Body Weight	Non-obese	67	7.49	1.972	2	10
	Obese	88	6.55	1.774	2	10
	Total	155	6.95	1.915	2	10
Comorbidities	Non-obese	66	3.21	1.696	2	8
	Obese	87	3.39	2.098	2	10
	Total	153	3.31	1.931	2	10
Neighbourhood Belonging	Non-obese	68	3.62	2.522	-4	6
	Obese	88	3.61	2.453	-4	6
	Total	156	3.61	2.475	-4	6
Neighbourhood Crime	Non-obese	68	-.12	.325	-1	0
	Obese	88	-.08	.378	-1	1
	Total	156	-.10	.355	-1	1
Community Activity	Non-obese	68	3.72	1.582	1	5
	Obese	87	3.38	1.601	1	5
	Total	155	3.53	1.597	1	5
Social Support	Non-obese	68	3.50	2.560	-5	6
	Obese	88	3.53	2.480	-5	6
	Total	156	3.52	2.507	-5	6
Number of contacts	Non-obese	68	2.97	1.106	0	6
	Obese	88	3.09	1.178	0	9
	Total	156	3.04	1.145	0	9

Descriptive statistics on measures for ethnicities

Descriptive Statistics: measures for ethnicities

		N	Mean	Std. Deviation	Min.	Max.
Anxiety	White European	130	8.60	5.039	0	21
	Black African/ other	11	5.56	4.891	0	14
	South Asian/Asian British	17	9.29	5.051	0	18
	Total	158	8.46	5.067	0	21
Depression	White European	130	4.86	3.850	0	20
	Black African/ other	11	3.45	3.643	0	11
	South Asian/Asian British	17	5.43	3.840	0	13
	Total	158	4.83	3.834	0	20
Timeline	White European	131	15.09	3.193	8	26
	Black African/ other	11	17.36	2.976	13	23
	South Asian/Asian British	17	14.18	2.899	10	23
	Total	159	15.15	3.201	8	26
Timecycle	White European	131	11.37	3.230	4	20
	Black African/ other	11	12.73	4.197	6	19
	South Asian/Asian British	17	11.92	2.976	6	18
	Total	159	11.52	3.277	4	20
Consequences	White European	131	13.80	4.034	6	26
	Black African/ other	11	14.73	4.077	6	22
	South Asian/Asian British	17	14.41	5.112	8	29
	Total	159	13.93	4.144	6	29
Personal Control	White European	131	17.66	3.697	6	27
	Black African/ other	11	18.09	5.300	7	30
	South Asian/Asian British	17	16.59	3.589	10	23
	Total	159	17.57	3.802	6	30
Treatment Control	White European	131	18.25	3.216	9	25
	Black African/ other	11	19.45	3.503	15	25
	South Asian/Asian British	17	18.24	3.817	10	24
	Total	159	18.33	3.295	9	25
Illness Coherence	White European	131	15.34	4.786	5	25
	Black African/ other	11	15.36	5.555	8	25
	South Asian/Asian British	17	14.91	5.472	5	25
	Total	159	15.29	4.884	5	25
Emotional Representation	White European	130	17.28	5.629	6	29
	Black African/ other	11	14.82	6.691	6	26
	South Asian/Asian British	17	17.95	5.806	6	27
	Total	158	17.18	5.726	6	29

Body Shape	White European	131	39.89	17.911	16	80
	Black African/ other	11	32.75	18.362	16	61
	South Asian/Asian British	17	35.57	12.956	16	66
	Total	159	38.93	17.519	16	80
Risk Factors [Knowledge]	White European	130	12.87	2.619	5	18
	Black African/ other	11	12.13	2.802	7	16
	South Asian/Asian British	17	12.20	3.438	5	17
	Total	158	12.74	2.722	5	18
Symptoms [Knowledge]	White European	131	10.97	2.496	3	15
	Black African/ other	11	11.22	3.003	6	17
	South Asian/Asian British	17	10.09	2.399	5	14
	Total	159	10.89	2.522	3	17
Preventative Health Behav.	White European	131	1.24	.431	1	2
	Black African/ other	10	1.40	.516	1	2
	South Asian/Asian British	17	1.47	.514	1	2
	Total	158	1.28	.450	1	2
Health Promoting Behav.	White European	131	1.44	.499	1	2
	Black African/ other	10	1.70	.483	1	2
	South Asian/Asian British	17	1.59	.507	1	2
	Total	158	1.47	.501	1	2
Health Harming Behav.	White European	125	7.06	2.092	2	10
	Black African/ other	11	7.45	1.635	6	10
	South Asian/Asian British	17	8.00	1.581	5	10
	Total	153	7.19	2.025	2	10
Perceived Body Weight	White European	130	6.92	1.967	2	10
	Black African/ other	11	6.82	1.834	4	9
	South Asian/Asian British	17	7.35	1.498	5	10
	Total	158	6.96	1.908	2	10
Comorbidities	White European	129	3.43	1.999	2	10
	Black African/ other	11	2.55	1.293	2	6
	South Asian/Asian British	16	2.94	2.175	2	10
	Total	156	3.31	1.983	2	10
Neighborhood Belonging	White European	131	3.34	2.506	-4	6
	Black African/ other	11	5.09	1.375	2	6
	South Asian/Asian British	17	4.59	2.093	0	6
	Total	159	3.60	2.459	-4	6
Neighborhood Crime	White European	131	-.11	.356	-1	1
	Black African/ other	11	-.09	.302	-1	0
	South Asian/Asian British	17	-.12	.332	-1	0
	Total	159	-.11	.348	-1	1
Community Activity	White European	130	3.61	1.568	1	5

	Black African/ other	11	3.18	1.779	1	5
	South Asian/Asian British	17	3.88	1.616	1	5
	Total	158	3.61	1.583	1	5
Social Support	White European	131	3.23	2.546	-5	6
	Black African/ other	11	5.00	1.342	2	6
	South Asian/Asian British	17	4.47	2.095	0	6
	Total	159	3.49	2.492	-5	6
Number of contacts	White European	131	2.91	.954	0	6
	Black African/ other	11	3.27	1.618	0	5
	South Asian/Asian British	17	3.35	1.057	1	5
	Total	159	2.98	1.026	0	6

Descriptive statistics on measures according to outcome variable of extended time

Descriptive Statistics: Measures to measures for extended time

		N	Mean	Std. Deviation
Anxiety	H-S within 2 weeks	82	8.62	5.063
	H-S 2 weeks or more	81	8.29	5.078
	Total	163	8.45	5.057
Depression	H-S within 2 weeks	82	4.75	3.570
	H-S 2 weeks or more	81	5.08	4.117
	Total	163	4.92	3.843
Timeline	H-S within 2 weeks	83	15.03	2.691
	H-S 2 weeks or more	81	15.29	3.607
	Total	164	15.16	3.170
Timecycle	H-S within 2 weeks	83	11.38	3.155
	H-S 2 weeks or more	79	11.71	3.405
	Total	162	11.54	3.273
Consequences	H-S within 2 weeks	83	13.77	3.943
	H-S 2 weeks or more	81	14.29	4.383
	Total	164	14.03	4.161
Personal Control	H-S within 2 weeks	83	17.32	3.824
	H-S 2 weeks or more	81	17.75	3.737
	Total	164	17.53	3.776
Treatment Control	H-S within 2 weeks	83	18.14	2.972
	H-S 2 weeks or more	79	18.52	3.569
	Total	162	18.33	3.272
Illness Coherence	H-S within 2 weeks	83	14.50	5.020
	H-S 2 weeks or more	80	16.07	4.684
	Total	163	15.27	4.906
Emotional Representation	H-S within 2 weeks	82	17.30	5.979
	H-S 2 weeks or more	80	17.19	5.502
	Total	162	17.25	5.731
Body Shape Questionnaire	H-S within 2 weeks	83	39.63	18.036
	H-S 2 weeks or more	81	38.55	16.835
	Total	164	39.09	17.408
Risk Factors [Knowledge]	H-S within 2 weeks	83	12.41	2.987
	H-S 2 weeks or more	79	13.10	2.338
	Total	162	12.75	2.705
Symptoms [Knowledge]	H-S within 2 weeks	83	10.77	2.677
	H-S 2 weeks or more	81	10.88	2.423
	Total	164	10.82	2.547
Preventative health Behav.	H-S within 2 weeks	83	1.02	.154

	H-S 2 weeks or more	80	1.58	.497
	Total	163	1.29	.457
Health Promoting Behav.	H-S within 2 weeks	83	1.06	.239
	H-S 2 weeks or more	80	1.93	.265
	Total	163	1.48	.501
Health Harming Behav.	H-S within 2 weeks	81	7.17	1.935
	H-S 2 weeks or more	77	7.26	2.080
	Total	158	7.22	2.001
Perceived Body Weight	H-S within 2 weeks	82	7.07	1.776
	H-S 2 weeks or more	81	6.78	2.055
	Total	163	6.93	1.920
Comorbidities	H-S within 2 weeks	83	3.46	2.126
	H-S 2 weeks or more	78	3.17	1.790
	Total	161	3.32	1.970
Neighbourhood Belonging	H-S within 2 weeks	83	3.33	2.293
	H-S 2 weeks or more	81	3.85	2.565
	Total	164	3.58	2.438
Neighbourhood Crime	H-S within 2 weeks	83	-.10	.370
	H-S 2 weeks or more	81	-.10	.339
	Total	164	-.10	.354
Community Activity	H-S within 2 weeks	83	3.87	1.496
	H-S 2 weeks or more	80	3.28	1.622
	Total	163	3.58	1.583
Social Support	H-S within 2 weeks	83	3.23	2.327
	H-S 2 weeks or more	81	3.75	2.591
	Total	164	3.48	2.467
Social Capital: Number of contacts	H-S within 2 weeks	83	2.92	.962
	H-S 2 weeks or more	81	3.15	1.256
	Total	164	3.03	1.119

APPENDIX N

Chapter 5: Frequency Table of all Ethnic Categories

Ethnicity

	Frequency	%	Valid %	Cumulative %
White	119	74.2	74.8	71.2
British	11	6.1	6.9	80.0
Other White	1	.3	.6	80.6
Black Caribbean	2	1.1	1.3	81.8
Black African	2	1.1	1.3	82.9
Asian	1	.3	.6	83.5
Other	0	0.0	0.0	85.3
Afro-Caribbean	3	1.5	1.9	87.6
South-Asian/Asian-British	2	1.1	1.3	88.8
Indian	11	6.1	6.9	97.6
Pakistani	1	.3	.6	98.2
Bangladeshi	1	.3	.6	98.8
Black	3	1.7	1.9	100.0
Total	159	96.6	100.0	
Missing	5	3.4		
Total	131	100.0		

APPENDIX O

Chapter 5: Correlation Matrix of Variables

		1	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34
1	Time to help-seeking	-																																
2	HHQ: Previous behav.	.012	-																															
3	HHQ:Health promoting behav.	-.082	.162*	-																														
4	HHQ: Health harming behav.	-.061	-.128	-.118	-																													
5	HHQ: Perceived body weight	.020	-.183*	.186*	.087	-																												
6	HHQ: Comorbidities	-.119	-.097	.124	.040	.225**	-																											
7	Neighborhood belonging	.119	.138	.157*	-.040	.041	.096	-																										
8	Neighborhood crime	-.171*	-.043	-.071	.178*	.011	.166*	.024	-																									
9	Community activity	.020	-.013	-.014	-.176*	-.033	-.007	.073	.008	-																								
10	Social support	.028	.062	.082	-.058	-.058	-.078	.209**	-.037	-.046	-																							
11	Number of contacts	-.020	.249**	.055	-.234**	.031	-.065	.225**	-.036	.069	.203**	-																						
12	Delay (2 wks)	.305**	-.013	-.106	-.061	-.031	-.157*	.118	.019	.054	.040	.001	-																					
13	Ethnicity White/BAME	.027	.142	.068	-.135	-.006	-.014	.224**	-.016	.136	-.003	.032	.148	-																				
14	Method of help-seeking	.101	-.048	-.029	.027	.044	-.110	.117	-.060	-.131	.157*	-.087	.258**	.014	-																			
15	Obese/Non-obese	.069	-.035	-.167*	-.008	-.297**	-.152	-.041	-.035	-.005	.104	-.084	-.221**	-.184*	-.011	-																		
16	Age	.054	-.096	.240**	-.065	.023	-.068	.018	.031	.167*	.030	.017	-.068	-.059	.110	.122	-																	
17	Employment	.045	.027	.040	-.041	.017	-.131	-.055	.068	.024	-.167*	.000	.097	.048	.129	-.008	.315**	-																
18	Years in the UK	-.210**	-.112	-.054	.104	.069	.046	-.128	-.052	.044	.077	.105	-.137	-.580**	-.017	.048	.036	.003	-															
19	BMI	.096	.090	-.238**	-.006	-.338**	-.140	.013	-.060	.003	.016	.024	-.148	.004	.031	.531**	-.027	-.041	.036	-														
20	HADS: Anxiety	.060	.041	-.240**	.110	-.121	-.068	-.355**	-.116	-.166*	-.028	-.029	-.056	-.070	-.096	.190*	-.191*	.072	-.033	.140	-													
21	HADS: Depression	.066	.058	-.330**	.121	-.170*	-.227**	-.303**	-.061	-.126	-.037	-.046	.054	-.006	.071	.244**	-.133	.142	-.050	.156*	.684**	-												
22	IPQ: timeline	.208**	-.146	.180*	.145	.118	-.049	.032	-.064	-.029	-.021	-.128	.039	.025	.074	.115	.061	.189*	-.021	.014	.024	.044	-											
23	IPQ: timecycle	.010	.028	-.161*	.153*	-.134	-.091	-.004	-.068	.070	.025	-.221**	.024	.127	.007	.139	-.176*	-.025	-.049	.180*	.187*	.185*	.147	-										
24	IPQ: consequenes	.141	-.025	-.278**	.184*	-.091	-.164*	-.022	-.067	-.098	.018	-.038	.080	.131	.082	.167*	-.125	.063	-.133	.223**	.392**	.393**	.262**	.310**	-									
25	IPQ: personal control	-.015	.027	.123	.064	.078	.065	.061	-.071	-.005	.057	.009	.002	-.041	.084	-.086	.019	.016	.001	.059	-.088	-.151*	.145	.088	-.024	-								
26	IPQ: treatment control	-.032	.175*	-.039	-.127	.046	.037	.058	-.102	.109	.032	-.017	.039	.069	-.065	-.016	.006	-.035	-.156*	.034	-.021	-.046	-.185*	.121	.031	.361**	-							
27	IPQ: illness coherence	.002	.063	.036	-.035	-.069	.021	.037	.033	.177*	-.009	.009	.132	-.025	.002	-.185*	-.143	-.015	-.108	-.124	-.167*	-.200**	-.017	-.194*	-.155*	.288**	.041	-						
28	IPQ: emotional rep.	.045	.102	-.091	.090	-.207**	-.089	-.149	-.102	-.134	.090	-.057	-.030	.042	-.072	.205**	-.120	.055	-.061	.155*	.576**	.445**	.155*	.434**	.577**	-.077	.102	-.310**	-					
29	BSQ	-.040	.085	-.254**	.118	-.353**	-.080	-.148	-.115	-.066	-.115	-.083	-.009	-.094	-.138	.128	-.418**	-.012	-.005	.237**	.421**	.386**	-.098	.254**	.210**	-.009	.080	.066	.343**	-				
30	Risk factor awareness	.044	.093	.149	-.032	.004	-.078	.110	-.101	-.084	.049	-.126	.137	-.070	.139	.015	-.026	.100	-.001	-.051	.021	.034	.032	-.025	-.080	.118	.176*	.067	.040	.124	-			
31	Personal risk	.049	.083	-.105	-.012	-.140	-.063	.025	-.147	-.106	.089	.163*	-.037	-.098	-.016	.184*	-.093	-.097	.114	.094	.276**	.272**	-.064	.034	.215**	.023	.048	-.082	.192*	.151*	.247**	-		
32	Symptom awareness	-.036	.035	.125	-.168*	-.142	-.146	-.033	-.031	.041	-.081	-.174*	.001	-.075	.075	-.074	.030	.035	.071	-.042	-.007	.016	.062	.003	-.143	.085	.048	.121	-.002	.113	.360**	.014	-	
33	Waist-to-hip ratio	.039	.114	-.022	.067	-.075	.092	.030	.012	-.179*	.154	-.048	.031	.012	-.063	.117	.044	-.096	-.036	.089	.055	.030	-.064	.068	.026	.099	.023	-.187*	.029	-.029	.067	-.026	-.136	-

** $p < 0.01$; * $p < 0.05$

APPENDIX P

Chapter 5: Results

R Code for the estimation and cross validation of the regression models

```
options(echo=TRUE)
options(comment="")
options(warnings=FALSE)

library(stargazer)
library(foreign)
library(bootStepAIC)
library(MASS)

cval=function(ay,py, dfmod){

  atab = matrix(nrow=6, ncol=6)

  atab[1, 1] = "Source"
  atab[1,2] = "Degrees of Freedom"
  atab[1,3] = "Sum of Squares"
  atab[1,4] = "Mean Squares"
  atab[1,5] = "F"
  atab[1,6] = "p(F)"

  atab[2,1] = "Model"
  atab[2,2] = dfmod

  SSm=0
  SSerr=0
  SStot=0

  for(i in 1:length(ay)){
    SSm = SSm + ((py[i]-mean(ay))^2)
    SSerr = SSerr + ((ay[i]-py[i])^2)
    SStot = SStot +((ay[i]-mean(ay))^2)
    }

  atab[2,3] = SSm
  atab[2,4] = SSm/dfmod

  atab[3,1] = "Error"
  dferr = (length(ay)-dfmod-1)
  atab[3,2] = dferr

  atab[3,3] = SSerr
  atab[3,4] = SSerr/dferr

  f=(SSm/dfmod)/(SSerr/dferr)
  atab[2,5] = (SSm/dfmod)/(SSerr/dferr)
  atab[2,6] = pf(q=f, df1=dfmod, df2=dferr, lower.tail=FALSE)
```

```
  atab[4,1] = "Total"
  atab[4,2] = length(ay)-1
  atab[4,3] = SStot

  atab[6,1] = "R^2 = "
  atab[6,2] = SSm/SStot

  return(atab)
  }

d=read.spss(choose.files(), use.value.labels=T, use.missings=T, to.data.frame=T)

dest = subset(d, Sample==1)
dval = subset(d, Sample==0)

cat("\nThe estimation sample contains ", nrow(dest), " participants and the validation sample contains
", nrow(dval), " participants.")

# Model Estimation

cat("Model Estimation")

d1 = dest[complete.cases(dest), ]

min.model = lm(Totaltime2~ 1, data=d1)
fwd.model = step(min.model, direction="forward", scope=(~ HADS_Anx + HADS_Dep + timeline +
timecycl + conseque + perscon + treatcon + illcoher + emotrepr + BSQ + RF + Personalrisk + SX +
WaistHipR + BMI_2 + ETH_CAT + GEN_ENG_2 + HHQPrevBxSUM + HHQHealthPromBxSUM
+ HHQHealthHarmBxSUM + HHQBWPercep + HHQComorbid + NeighborhoodBelongSUM +
NeighborhoodCrimeSUM + CommunityActivitySUM + Socialsupport + Contacts), trace=F)

summary(fwd.model)

form=formula(fwd.model$call)

lfit = lm(formula=form, data=d1)
bfit= boot.stepAIC(lfit,data=dest,B=5000, direction="both") # this calculation will take several
minutes

cat("\n\n The optimised model from the original data is\n\n")
print(bfit$OrigStepAIC)

s=data.frame(bfit$Sign)
names(s) = c("Positive Sign", "Negative Sign")
s = s[order(row.names(s)),]
si=bfit$Significance
si=data.frame(si)
si = si[order(row.names(si)),]
s = data.frame(s, "Significant" = si)
s=data.frame(row.names(s), s[,3], s[,1], s[,2])
names(s) = c("Covariate"," % Significant", "% Positive Coeff", "% Negative Coef")
print(s[order(-s[,2]),])
```

```
# the estimate of the final model from the entire estimation sample

efit1 = lm(Totaltime2 ~ HHQPrevBxSUM + BMI_2 + NeighborhoodCrimeSUM + emotrepr,
data=dest)
efit2 = lm(Totaltime2 ~ HHQPrevBxSUM + BMI_2 + NeighborhoodCrimeSUM, data=dest)

summary(efit1)
summary(efit2)

# validation

a = dval$Totaltime2

p1 = predict(efit1, newdata=dval)
p2 = predict(efit2, newdata=dval)

dv = data.frame(a, p1, p2)
dv=dv[complete.cases(dv),]

a = dv$a
p1=dv$p1
p2=dv$p2

print(efit1$call)
t=cval(ay=a, py=p1, dfmod=4)
stargazer(t,digits=2,type="text")

print(efit2$call)
t=cval(ay=a, py=p2, dfmod=3)
stargazer(t,digits=2,type="text")
```

T-test: Gynaecological awareness (symptoms) and obesity

Group Statistics

	Obese	N	Mean	Std. Deviation	Std. Error Mean
Symptoms	Non-obese	74	10.85	2.474	.288
	Obese-Morbidly obese	91	10.79	2.566	.269

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Symptoms	Equal variances assumed	.183	.670	.155	163	.877	.061	.395	-.719	.842
	Equal variances not assumed			.155	158.332	.877	.061	.394	-.717	.839

T-test: Gynaecological awareness (risk factors) and obesity

Group Statistics

	Obese	N	Mean	Std. Deviation	Std. Error Mean
Risk factors	Non-obese	75	12.88	2.752	.318
	Obese-Morbidly obese	90	12.60	2.853	.301

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Risk factors	Equal variances assumed	.012	.914	.622	163	.535	.273	.439	-.594	1.140
	Equal variances not assumed			.624	159.510	.534	.273	.437	-.591	1.137

Chi-square test: Knowledge of obesity as a risk factor obese and non-obese

Chi-Square Tests: Testing for difference in knowledge of obesity as a risk fact across groups of obese/non-obese

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.454[a]	1	.500		
Continuity Correction[b]	.243	1	.622		
Likelihood Ratio	.457	1	.499		
Fisher's Exact Test				.589	.312
Linear-by-Linear Association	.451	1	.502		
N of Valid Cases	155				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 18.86.

b. Computed only for a 2x2 table

Chi-square test: Knowledge of obesity as a risk factor across ethnicities

Chi-Square Tests: Testing for difference in knowledge of obesity as a risk fact across groups of obese/non-obese

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	.705[a]	2	.703
Likelihood Ratio	.670	2	.715
Linear-by-Linear Association	.320	1	.572
N of Valid Cases	158		

a. 2 cells (33.3%) have expected count less than 5. The minimum expected count is 2.92.

Oneway ANOVA for ethnicity and gynaecological cancer knowledge (symptoms & risk-factors) and extended time to help-seeking 2 weeks

Descriptive Statistics

		N	Mean	Std. Deviation
Risk Factors [Knowledge]	White European	130	12.87	2.619
	Black African/ other	11	12.13	2.802
	South Asian/Asian British	17	12.20	3.438
	Total	158	12.74	2.722
Symptoms [Knowledge]	White European	131	10.97	2.496
	Black African/ other	11	11.22	3.003
	South Asian/Asian British	17	10.09	2.399
	Total	159	10.89	2.522

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
Symptoms	Between Groups	12.863	2	6.432	1.011	.366
	Within Groups	992.077	155	6.359		
	Total	1163.368	158			
Risk factors	Between Groups	11.184	2	5.592	.752	.473
	Within Groups	11152.184	155	7.433		
	Total	1163.368	157			

Group Statistics

	Delay_2wk	N	Mean	Std. Deviation	Std. Error Mean
Symptoms	Within 2 wks	83	10.77	2.677	.294
	More than 2 wks	80	10.91	2.429	.272
Risk factors	Within 2 wks	83	12.41	2.987	.328
	More than 2 wks	78	13.18	2.247	.254

APPENDIX Q

Chapter 6: Results

Chi-square tests between White European/BME participants and obesity according to BMI

Ethnicity WE/BME groups and Obesity (BMI) Crosstabulation

			Obese		Total
			Non-obese	Obese	
Ethnicity White/ BME	White European	Count	58	69	127
		% within Ethnicity WE/BME	45.7%	54.3%	100.0%
		% within Obese	78.4%	79.3%	78.9%
		% of Total	36.0%	42.9%	78.9%
	BME	Count	16	18	34
		% within Ethnicity WE/BME	47.1%	52.9%	100.0%
		% within Obese	21.6%	20.7%	21.1%
		% of Total	9.9%	11.2%	21.1%
Total		Count	74	87	161
		% within Ethnicity WE/BME	46.0%	54.0%	100.0%
		% within Obese	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.021[a]	1	.885		
Continuity Correction[b]	.000	1	1.000		
Likelihood Ratio	.021	1	.885		
Fisher's Exact Test				1.000	.518
Linear-by-Linear Association	.021	1	.886		
N of Valid Cases	161				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 15.63.

b. Computed only for a 2x2 table

* *WE= White European; BME = Black, Asian and minority ethnic groups*

Chi-square tests: White European & British, Asian and minority ethnic (BME) participants regarding waist-to-hip ratio

WE/BME groups and Obesity (Waist-hip ratio) Crosstabulation

			WHR_OB_NO		Total
			Non-obese (.85 or less)	Obese (>.85)	
Ethnicity WE/ BME	White European	Count	66	57	123
		% within Ethnicity WE/BME	53.7%	46.3%	100.0%
		% within WHR_OB_NO	81.5%	80.3%	80.9%
		% of Total	43.4%	37.5%	80.9%

	BME	Count	15	14	29
		% within Ethnicity WE/BME	51.7%	48.3%	100.0%
		% within WHR_OB_NO	18.5%	19.7%	19.1%
		% of Total	9.9%	9.2%	19.1%
Total		Count	81	71	152
		% within Ethnicity WE/BME	53.3%	46.7%	100.0%
		% within WHR_OB_NO	100.0%	100.0%	100.0%
		% of Total	53.3%	46.7%	100.0%

* *WE= White European; BME = Black, Asian and minority ethnic groups; WHR = Waist-hip-ratio; OB = Obese; NO = Not obese*

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.035[a]	1	.851		
Continuity Correction[b]	.000	1	1.000		
Likelihood Ratio	.035	1	.851		
Fisher's Exact Test				1.000	.506
Linear-by-Linear Association	.035	1	.852		
N of Valid Cases	152				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 13.55. b. Computed only for a 2x2 table

Method of medical help-seeking: Frequency table

Method of help-seeking Frequency Table

Medical help-seeking type		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	A&E	6	3.4	3.5	3.5
	GP	134	76.1	77.9	81.4
	Other: Smear/comorbid_ apt	32	18.2	18.6	100.0
	Total	172	97.7	100.0	
Missing	99	4	2.3		
Total		176	100.0		

Presence of concern before medical help-seeking: Frequency table

Presence of Concern Frequency Table

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No concern	20	11.4	11.8	11.8
	Concern present	150	85.2	88.2	100.0
	Total	170	96.6	100.0	
Missing	99	6	3.4		
Total		176	100.0		

APPENDIX R

Chapter 6: Results of Methods to Help-seeking and the Journey to Help-seeking

Descriptive Statistics: Detection to Concern and Methods of Help-seeking

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
A&E	6	10.33	25.311	10.333	-16.23	36.90	0	62
GP	127	19.04	104.612	9.283	.67	37.41	0	903
Other: Smear/comorbid apt	32	80.06	322.595	57.027	-36.25	196.37	0	1810
Total	165	30.56	169.395	13.187	4.52	56.60	0	1810

Oneway ANOVA: Methods of Help-seeking and Days from Detection to Concern

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	97726.692	2	48863.346	1.718	.183
Within Groups	4608206.011	162	28445.716		
Total	4705932.703	164			

Descriptive Statistics: Booking to attendance and methods of help-seeking

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean	
					Lower Bound	Upper Bound
A&E	6	.17	.408	.167	-.26	.60
GP	128	3.17	4.869	.430	2.32	4.02
Other: Smear/comorbid_apt	32	9.53	30.952	5.472	-1.63	20.69
Total	166	4.29	14.323	1.112	2.09	6.48

Oneway ANOVA of methods of help-seeking and days from booking to attendance

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1141.100	2	570.550	2.843	.061
Within Groups	32709.021	163	200.669		
Total	33850.120	165			

Descriptive Statistics: Total time to help-seeking

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean	
					Lower Bound	Upper Bound
A&E	6	171.67	372.334	152.005	-219.07	562.41
GP	126	106.07	475.669	42.376	22.20	189.94
Other: Smear/comorbid_apt	32	244.41	584.995	103.414	33.49	455.32
Total	164	135.46	495.879	38.722	59.00	211.92

Oneway ANOVA: Methods of Help-seeking and Total time to Help-seeking

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	496507.371	2	248253.686	1.010	.367
Within Groups	39584613.409	161	245867.164		
Total	40081120.780	163			

APPENDIX S

Chapter 6: Results of Flow Chart Mapping Intervals Between Events for Obese and Non-obese groups

Descriptive Statistics for all participants

		Detect to booking	Detect to concern	Concern	Booking to attend	Visits for Referral	Total time
N	Valid	164	166	170	166	166	164
	Missing	12	10	6	10	10	12
Mean		128.70	30.40	.88	4.29	1.41	135.46
Std. Deviation		496.272	168.894	.323	14.323	4.582	495.879

Event 1: Days from detection to concern for obese and non-obese women: t-test

Descriptive Statistics

	Obese	N	Mean	Std. Deviation	Std. Error Mean
Detect to concern	Non-obese	71	33.00	214.462	25.452
	Obese	87	20.43	90.918	9.747

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Detect to concern	Equal variances assumed	.600	.440	.495	156	.621	12.575	25.386	-37.571	62.720
	Equal variances not assumed			.461	90.456	.646	12.575	27.255	-41.568	66.717

A chi-square test between the obese and non-obese women and the presence of concern before seeking help

Obesity and Concern Crosstabulation

			Concern			Total
			No concern	Concern present	3	
Obese	Non-obese	Count	7	67	0	74
		% within Obese	9.5%	90.5%	0.0%	100.0%
		% within Concern	38.9%	46.9%	0.0%	45.7%
		% of Total	4.3%	41.4%	0.0%	45.7%
	Obese	Count	11	76	1	88
		% within Obese	12.5%	86.4%	1.1%	100.0%
		% within Concern	61.1%	53.1%	100.0%	54.3%
		% of Total	6.8%	46.9%	0.6%	54.3%
Total		Count	18	143	1	162
		% within Obese	11.1%	88.3%	0.6%	100.0%
		% within Concern	100.0%	100.0%	100.0%	100.0%
		% of Total	11.1%	88.3%	0.6%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.255[a]	2	.534
Likelihood Ratio	1.638	2	.441
Linear-by-Linear Association	.019	1	.891
N of Valid Cases	162		

a. 2 cells (33.3%) have expected count less than 5. The minimum expected count is .46.

Event 2: Days from detection to booking for obese and non-obese women: t-test

Descriptive Statistics

	Obese	N	Mean	Std. Deviation	Std. Error Mean
Detection to booking	Non-obese	71	112.37	422.046	50.088
	Obese	85	152.82	572.170	62.060

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Detection to booking	Equal variances assumed	1.179	.279	-.494	154	.622	-40.457	81.907	-202.264	121.349
	Equal variances not assumed			-.507	151.789	.613	-40.457	79.751	-198.023	117.109

Event 3: Days from booking to attendance to healthcare for obese and non-obese women: t-test

Descriptive Statistics

	Obese	N	Mean	Std. Deviation	Std. Error Mean
Book to attend	Non-obese	71	3.68	5.366	.637
	Obese	86	4.90	19.276	2.079

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Booking to attendance	Equal variances assumed	1.743	.189	-.516	155	.606	-1.219	2.361	-5.883	3.444
	Equal variances not assumed			-.561	100.630	.576	-1.219	2.174	-5.532	3.093

Event 4: Referral and methods of help-seeking (Emergency services, GP surgery, Other): Descriptive Statistics & T-test

Descriptive Statistics

	Referral	N	Mean	Std. Deviation	Std. Error Mean
Help-seeking method	Immediate referral	156	2.17	.466	.037
	2+ visits before referral	10	2.00	.000	.000

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Help-seeking method	Equal variances assumed	11.672	.001	1.128	164	.261	.167	.148	-.125	.458
	Equal variances not assumed			4.467	155.000	.000	.167	.037	.093	.240

Referral from first visit for obese and non-obese women: Chi-square test

Referral from first visit and Obesity Crosstabulation

Count		Obese		Total
		Non-obese	Obese	
Referral visits	0	0	1	1
	Immediate referral	67	80	147
	2+ visits before referral	4	5	9
	60	0	1	1
Total		71	87	158

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.658[a]	3	.646
Likelihood Ratio	2.412	3	.491
Linear-by-Linear Association	.791	1	.374
N of Valid Cases	158		

a. 6 cells (75.0%) have expected count less than 5. The minimum expected count is .45.

Visits for Referral Frequency Table

	Frequency	Percent	Valid %	Cumulative %
0	1	.6	.6	.6
Immediate referral	154	87.5	92.8	93.4
2+ visits before referral	10	5.7	6.0	99.4
60	1	.6	.6	100.0
Total	166	94.3	100.0	
Missing	99	10	5.7	
Total		176	100.0	

Total time to help-seeking from detection to medical help-seeking for non-obese and obese: t-test

Descriptive Statistics

	Obese	N	Mean	Std. Deviation	Std. Error Mean
Total time	Non-obese	69	118.91	427.166	51.425
	Obese	86	160.81	568.471	61.300

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Total time	Equal variances assumed	1.090	.298	-.508	153	.612	41.901	82.510	204.906	121.104
	Equal variances not assumed			-.524	152.392	.601[a]	41.901	80.014	199.980	116.178

APPENDIX T

Chapter 6: Results of Flow Chart Mapping Events for White European and Black, Asian and Minority Ethnic group (BME)

Event 1: Days from detection to concern for White European and BME groups: t-test

Descriptive Statistics

	Ethnicity WE/BME	Mean	Std. Deviation	Std. Error Mean
Detection to concern	White European	27.13	176.835	15.450
	BME	48.73	146.953	26.830

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Detection to concern	Equal variances assumed	.604	.438	-.621	159	.535	-21.604	34.767	-90.269	47.062
	Equal variances not assumed			-.698	50.191	.489	-21.604	30.960	-83.783	40.576

Chi-square test between the White European and BME groups and the presence of concern before seeking help

Ethnicity: White European/BME groups and Concern Crosstabulation

			Concern			Total
			No concern	Concern present	3	
Ethnicity W/BME	White European	Count	17	115	1	133
		% within Ethnicity W/BME	12.8%	86.5%	0.8%	100.0%
		% within Concern	85.0%	79.9%	100.0%	80.6%
		% of Total	10.3%	69.7%	0.6%	80.6%
	Non-white	Count	3	29	0	32
		% within Ethnicity W/BME	9.4%	90.6%	0.0%	100.0%
		% within Concern	15.0%	20.1%	0.0%	19.4%
		% of Total	1.8%	17.6%	0.0%	19.4%
Total		Count	19	144	1	164
		% within Ethnicity W/BME	12.1%	87.3%	0.6%	100.0%
		% within Concern	100.0%	100.0%	100.0%	100.0%
		% of Total	12.1%	87.3%	0.6%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	.539[a]	2	.764
Likelihood Ratio	.745	2	.689
Linear-by-Linear Association	.070	1	.792
N of Valid Cases	164		

a. 3 cells (50.0%) have expected count less than 5. The minimum expected count is .19.

Event 2: Days from detection to booking for White European and Black Minority Ethnic groups: t-test

Descriptive Statistics

	Ethnicity WE/BME	N	Mean	Std. Deviation	Std. Error Mean
Detection to booking	White European	131	109.20	471.947	41.234
	BME	28	174.68	552.572	104.426

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Detection to booking	Equal variances assumed	.679	.411	-.646	157	.519	-65.480	101.345	-265.656	134.695
	Equal variances not assumed			-.583	35.895	.563	-65.480	112.272	-293.202	162.242

Event 3: Time from booking to attendance for White European and Black Minority Ethnic groups: t-test

Descriptive Statistics

	Ethnicity WE/BME	N	Mean	Std. Deviation	Std. Error Mean
Book to attend	White European	131	3.84	13.661	1.194
	BME	29	3.48	4.990	.927

** WE= White European; BME = Black, Asian and minority ethnic groups*

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Book to attend	Equal variances assumed	.274	.601	.138	158	.890	.357	2.579	-4.738	5.451
	Equal variances not assumed			.236	124.294	.814	.357	1.511	-2.634	3.348

Event 4: Referral from first visit for White European and BME groups: Chi-square test

Number of visits for referral and Ethnicity WE/BME Crosstabulation

Count		Ethnicity WE/BME		Total
		White European	Non-white	
Referral visit	Immediate referral	126	25	151
	2+ visits before referral	6	4	10
Total		132	29	161

WE= White European; BME = Black, Asian and minority ethnic groups;
WHR = Waist-hip-ratio; OB = Obese; NO = Not obese

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.490[a]	1	.062		
Continuity Correction[b]	2.083	1	.149		
Likelihood Ratio	2.857	1	.091		
Fisher's Exact Test				.082	.082
Linear-by-Linear Association	3.469	1	.063		
N of Valid Cases	161				

a. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 1.80.

b. Computed only for a 2x2 table

T-test: Total time to help-seeking from detection to medical help-seeking for non-obese and obese

Descriptive Statistics

	Ethnicity WE/BME	N	Mean	Std. Deviation	Std. Error Mean
Total time	White European	130	113.91	473.097	41.493
	BME	28	192.50	552.260	104.367

** WE= White European; BME = Black, Asian and minority ethnic groups*

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Total time	Equal variances assumed	.855	.357	-.773	156	.440	-78.592	101.612	-279.306	122.122
	Equal variances not assumed			-.700	36.022	.489	-78.592	112.313	-306.369	149.185

APPENDIX U

Chapter 7: Participant Information Sheet for Interview

Sandwell & West Birmingham Hospitals NHS Trust NHS UNIVERSITY OF BIRMINGHAM

Location: Sandwell Hospital PMB Clinic

Information Sheet for Participants (Phase 2)

Study Title: *Help-seeking for post-menopausal bleeding symptoms: An interview study*

Introduction
My name is Sara Tookey and I am a Doctoral Researcher at the University of Birmingham. I would like to invite you to take part in a study in an interview study. Please take the time to read through the following information. Ask a staff member or researcher if you have any questions or would like more information.

What is the purpose of the study?
The purpose of the study is to explore your experience of help-seeking in greater detail. We are interested in hearing about your experience of seeking help for your gynaecological symptoms (from the moment you recognised that something was not right, until now) and whether or not body image or size plays and role in this experience.

Why have I been chosen?
Any woman who attends the Post-menopausal Bleeding Clinic and is identified by a consultant as meeting the eligibility criteria of having a BMI of 40 or above.

Do I have to take part? / What happens if I take part?
To participate in this study you will have participated in *Part 1* of the study to complete associated questionnaire. Upon completion of the questionnaire, an interview will be scheduled (or a time convenient to you) at the clinic with the researcher. Your consultant will have identified you as eligible to participate in this study. The interview allows you to share your experience and expand on the answers you provided in the questionnaire. You may bring along a partner or trusted friend to help you recall the events leading up to you seeking help and to support you during this process if you wish. If you do feel distressed at any point regarding the interviewer please share this with the interviewer who will be there to provide you with support during the process. Contact information for further support will be given after completion of the interview.

The information you provided in the questionnaire will be used to explore your responses and to allow you to share your experience in a conversational environment. You are invited to bring a partner or close friend/family member to the interview to support you and help you to recall certain events that may have occurred around the time you first noticed your bodily change.

Even if you decide to take part, *you are free to withdraw from the study at any time up until a month after completion of the interview*, without having to give any reason. Withdrawing from the study will not affect your care or have any negative consequences on your circumstances. You may also choose to withdraw from any part of the study and request for all or part of your data to be destroyed.

What happens to my information?
All information that is obtained from the interview will be uploaded onto a password-protected computer and any paper material will be stored in a locked filing cabinet at the University of Birmingham where only the study researchers will have access to this information. Interviews will be audio-recorded for the purpose of transcribing your spoken words into text for analysis and direct quotations will be used in

reporting results. However, these quotes would not contain any information that would allow you to be identified. Only the research team will have access to original materials. This material will be anonymised (i.e. references to people, places, organisations and other potentially identifying material) and systematically altered in the transcripts. Participants and all participant data (including audio files), will be identified by numbers, and can therefore not be traced back to you or anyone else. Once the audio files are transcribed digital copies will be deleted. Your name will only appear on your consent form, and the researcher will be the only person who has access to a list linking your name with your number.
All data will be stored securely at the University according to the University of Birmingham's Code of Practice for Research for 10 years.

Will my taking part in this study be kept confidential?
All information that is obtained during the course of the study will be kept strictly confidential. No identifiable information will be included in any publication using the data of this study. Your responses will not be passed onto your clinical care team. Good Clinical Practice codes will be followed and if you should happen to disclose intent to harm yourself or others, a clinic staff member will be informed and clinic/trust policy will determine appropriate safety response action.

What will happen to the results of the study?
The results of the study will be analysed by the research team to identify motivators and barriers to help-seeking for women who have sought help for abnormal gynaecological symptoms. The results may be presented at a conference or published in an academic journal and may be used to inform future research regarding the experience coming to seek help for potential symptoms of gynaecological cancer. Please note that no identifiable information will be released in any write-up of the results. If you choose to participate in the study you may request to receive a copy of the results by contacting the researcher.

Please contact SWBH Patient PALS advice and liaison service (PALS) for hospital/trust assistance you have concerns or complaints regarding this research: 0121 507 5836

Please contact Sara Tookey with any questions or if you have not yet indicated your interview time preference. Sara will then arrange a date and time that is convenient.

Primary Researcher: **Sara Tookey** PhD Researcher School of Psychology University of Birmingham Edgbaston, Birmingham	Supervisory Researcher: Dr. Beth Grunfeld Senior Lecturer and Research Supervisor School of Psychology University of Birmingham Edgbaston, Birmingham
ervisor at Clinic: Mr. Joe Kabukoba, MD Post-menopausal Clinic Consultant Sandwell Hospital Sandwell & West Birmingham Hospitals NHS Trust	ervisor at Clinic: Mrs. Shagaf Bakour, MD Consultant Gynaecologist, Birmingham City Hospital Sandwell and West Birmingham Hospitals NHS

APPENDIX V

Chapter 7: Participant Consent Form for Interview

Sandwell & West Birmingham Hospitals NHS Trust NHS UNIVERSITY OF BIRMINGHAM

Help-seeking for post-menopausal bleeding symptoms: An interview study

Consent Form for Participants

Please tick each statement to the left **AND initial** to the right of each statement indicate agreement.

☐ I have read and understood the information sheet for the above study and have been given the opportunity to ask questions. __________

☐ I understand that my participation is voluntary and that I am free to withdraw from the study up until __________ *(the specific date will be entered here on the day of the interview)* without having to give any reason and without me being affected or this having any negative consequences on my circumstances. __________

☐ I agree to provide information that will be used for research purposes only, and understand that all the information relating to myself obtained as part of the study will be strictly confidential, and that I will not be personally identified in any write-up of the results. __________

☐ I understand that relevant data collected during the study may be looked at by individuals from the University of Birmingham's Psychology research team, and from regulatory authorities of the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. __________

☐ I understand that information will be stored in secured manual and electronic files and is subject to the provisions of the Data Protection Act. __________

☐ I consent to being audio-taped for the purpose of transcription and that the audio data will be deleted once transcription is complete. __________

☐ I understand that the Good Clinical Practice codes will be followed and as such, if you should happen to disclose intent to harm yourself or others, a clinic staff member will be informed and clinic/trust policy will determine appropriate safety response action. __________

☐ I wish to participate in this study under the conditions set out here and in the Information Sheet for Participants.

Printed Name: ______________________________ Signature: __________________________

Researcher Signature: ______________________________

Date Agreed: ________________

Thank you very much for agreeing to participate in this study!

APPENDIX W

Chapter 7: Interview Schedule

Version1.8- amended

Introduction:

I wonder if we could begin by having you tell me a bit about why you were referred to the
PMB clinic and what the results of your investigation was?
    How does that make you feel to know that you do not have a diagnosis?

1. Menopause

Could you please tell me about your experience with menopause?
    Symptoms, changes in your body at the time?
How would you describe your body image at the time?
    How did you feel about your body and the changes you were experiencing?
    How did you understand what was happening in your body at that time?
Did you make use of your healthcare professional or GP during this time?
    Medicine?
    Did your GP discuss weight or weight changes with you during this time?

2. Recognition of change (symptom)

After you'd stopped bleeding, when did you notice bleeding or a change in your body?
    What happened? What was that like for you?
How did you understand what was happening?
    Or the experience of you as a women?
    What does it mean for you as a woman?

3. Concern

When did you notice that it was something to be concerned about?
    Why was it concerning? /What were your worries?
What was your visit to the GP/HCP like?
    How did you feel about the visit?
    Expectations?
    How did it go?
    What BI brought up as an issue in this conversation at all?

4. Is there anything that you might have done differently (looking back)?

    Do you think you made the choices that others would?
    Or was it based on things that were important specifically to you?

Original Interview Schedule

Version 1.8

Introduction:

Thank you again for meeting with me today. This interview should last roughly one hour and will be flow more like a conversation than a structured interview. I do have some specific questions that I will be asking, but please know that there are no right or wrong answers here. I am here to learn from you and to hear about your own experiences gynaecological symptoms, which lead you to seek help from the Post Menopausal Clinic.

I wonder if we could begin by having you tell me a bit about why you were referred to the PMB clinic and what the results of your investigation was?

How does that make you feel to know that you do not have a diagnosis?

1. Step 1: First Recognition of change

Could you please tell me when it was that you first noticed that something was not quite right with your body?

Could you describe this symptom for me?

What did you think it might be at first?

When was this?

What else was going on during this time? (Mark date on blank calendar provided)

Where were you and what was going on at the time?

What was that like for you?

What was that like for those around you?

At the time what did you think was causing this?

Did you think your weight, size or body shape had anything to do with this?

2. Step 2: Recognition of concern

When did you first become concerned with this symptom/bodily change __(will use participant's identifying word for their experience here)? (Mark date on blank calendar provided)

What were your concerns about this?

How long did this concern last for? Please explain this for me.

What did you do in response to this concern? (for example, did you speak to a friend, seek the help of a healthcare professional, etc.)

How well did these work in relieving your concern?

I wonder whether there were things going on in your social or personal life that could have affected the way you responded to this __ (again will use participant's own words to describe the identity of their experience).

Could there have been things you did or didn't do as a result of this concern?

Was you weight a consideration at all in how you decided to respond to this concern?

Were you able to confide in another person? What was this like?

Who was this person and what did you discuss?
How long did it take you to open up to another person? (Mark on calendar when they confided in another person)
How did the other person respond?

3. Booking the Doctor's appointment/ seeking immediate help

When did you realise that this was an issue that needed to be assessed by a medical healthcare professional? (Mark date on blank calendar provided)
What was it like when you realised this?
How did you feel about it?
What is it like for you to see a doctor for a medical concern?
When was the last time you saw a doctor and what was that like for you?

Were there issues or concerns that you had to consider booking an appointment?
What things made it difficult for you to make when contact with a healthcare professional?
Again I'm wondering if there were things going on in you social, professional or personal life that could have affected the way you responded to this __ (again will use participant's own words to describe the identity of their experience).
Also, were there things that you had to consider regarding you weight or body size that you think a slimmer person may not need to consider?

How did you make the first contact to see a healthcare professional for your __ (again will use participant's own words to describe the identity of their experience)?
Why did you arrange a visit?
If you sought immediate/ urgent care how did you do this?
What was this experience like for you?
How easy or difficult was it and why?

Were there things going on in your social, professional or personal life that could have affected the way you responded to this __ (again will use participant's own words to describe the identity of their experience).

How did you feel just before you made contact?
How did you feel during?
How did you feel after you made the phone call?

When was your appointment arranged for? (Mark on calendar provided)

What was it like to wait for your appointment?

4. Attending the doctor's appointment

When did you attend your initial doctor's appointment for this__ (again will use participant's own words to describe the identity of their experience)? (Mark on calendar provided)-if date attended is different than the date booked from previous question, will enquire about reason for this change and possible cancellation of previous appointment(s).

- How was it getting there (logistically, physically, emotionally)?
- How did you feel on the day?
- What concerns did you have about your visit?
- What did you plan to say to the doctor?
- What was the office like?
  - Where there things about the aesthetics, staff attitudes or accessibility of services that made this experience challenging or difficult for you? If so what were they?
    - What was that like for you?
  - How were you treated by staff?
  - How did you feel waiting for your appointment in the clinic?

What did you explain was the issue to your doctor?

- How did the doctor respond to you?
- Do you feel that your doctor understood your concerns? How do you know this?
- What did your doctor do in response?

Was there an examination? If so, what was that like for you?

- How did the way you feel about your body affect the way you experienced this?
- How did your weight play a role in how you experienced this?

- How did your culture or values play a role in how you experienced this?

Did you receive a referral for the post-menopausal bleeding clinic during this appointment?

- If so, what was that like to hear that you needed this referral?
- If not, what did the doctor assume was the issue?
  - What advice or solution did they give you for your problem?

5. Assessing for barriers and delay

If situations where different do you think you could have sought help sooner?

- What would have needed to be different?
- Could your weight have anything have impacted your time to seeking help? If so, how?
  - What issues did you have to face in this process that perhaps a slimmer woman would not?
- Could you explain if you think your social or cultural values may have affected this time to seeking help from a doctor (by slowing or speeding up the time to seeking help from the moment you noticed your __ (again will use participant's own words to describe the identity of their experience) to the moment you sought help from a healthcare professional?

APPENDIX X

Chapter 7: Participant Debrief Form for Interview

Sandwell & West Birmingham Hospitals NHS Trust

Location: Sandwell General Hospital PMB Clinic

UNIVERSITY OF BIRMINGHAM

Debriefing form (Interview study)

Study Title: *Help-seeking for gynaecological symptoms: An Interview Study*

Thank you for choosing to participate in this research study.

Thank you again for agreeing to participate in this interview investigating the experience of seeking help for your gynaecological symptoms, from the moment of symptom recognition to Post-menopausal clinic appointment. In this interview we used the answers you provided in the questionnaire study you participated in to guide an in-depth interview. We were interested in your individual experience of seeking help for your symptom, your feelings about attending your medical appointments and what motivated you or stood in the way of you seeking medical help. We were also interested to understand the other things you did to cope with your symptom (for example, seeking advice from a family or friend).

You were approached to participate, as you attended Post-menopausal bleeding services and met the inclusion criteria for this study.

If you would like to speak with someone with any concerns that may have been brought to light by this research please speak with a clinic staff member. Any questions regarding the research please contact the researchers below.

What next? Your study participation is complete. We will access your chart notes through the clinic and will acquire your weight and height and body fat percentage, which is measured by the clinic healthcare professional. In the next six months the researcher will access you chart notes once more to confirm the presence or lack of diagnosis.

Even if you decided to take part, you are still free to withdraw from the study at any time up until **a month post after completion of the questionnaire and interview**, without having to give any reason. Withdrawing from the study will not affect you or have any negative consequences on your circumstances. If you wish to withdraw please contact the researcher below (Sara Tookey).

What happens to my information?

All information that is obtained from the questionnaire will uploaded onto a password-protected computer and paper questionnaires will be stored in a locked filing cabinet at the University of Birmingham where only the study researchers will have access to this information. This information will then be entered into a computer database, where your information will be assigned a number. The information in the database, as well as all study material will be identified by numbers, and can therefore not be traced back to you or anyone else. Your name will only appear on your consent form, and the researcher will be the only person who has access to a list linking your name with your number.

Your clinic chart will be accessed twice (as stated above). Your personal information will not be linked to the data at any time and will be coded so that you will not be identifiable in the study data. NHS trust policies will be followed in accessing clinic notes and no identifying data will be linked with the data.
All data will be stored securely at the University according to the University of Birmingham's Code of Practice for Research for 10 years.

Will my taking part in this study be kept confidential?
Yes. All information that is obtained during the course of the study will be kept strictly confidential. No identifiable information will be included in any publication using the data of this study. Good Clinical Practice codes will be followed and if you should happen to disclose intent to harm yourself or others, a clinic staff member will be informed and clinic/trust policy will determine appropriate safety response action.

What will happen to the results of the study?
The results of the study will be analysed by the research team to identify the barriers to help-seeking for women who have sought help for abnormal gynaecological symptoms and will explore factors that may impact process of coming to seek help for such symptoms. The results may be presented at a conference or published in an academic journal and may be used to inform future research regarding the experience coming to seek help for potential symptoms of gynaecological cancer. Please note that no identifiable information will be released in any write-up of the results. If you choose to participate in the study you may request to receive a copy of the results by contacting the researcher.

Please contact SWBH Patient PALS advice and liaison service (PALS) for hospital/trust assistance you have concerns or complaints regarding this research: 0121 507 5836

Primary Researcher: **Sara Tookey** PhD Researcher School of Psychology University of Birmingham Edgbaston, Birmingham	Supervisory Researcher: Dr. Beth Grunfeld Senior Lecturer and Research Supervisor School of Psychology University of Birmingham Edgbaston, Birmingham B15 2TT
ervisor at Clinic: Mr. Joe Kabukoba, MD Post-menopausal Clinic Consultant Sandwell Hospital Sandwell & West Birmingham Hospitals NHS Trust	Consultant Supervisor at Clinic: Mrs. Shagaf Bakour, MD Consultant Gynaecologist, Birmingham City Hospital Sandwell and West Birmingham Hospitals NHS

APPENDIX Y

Chapter 7: Case Summaries

SUE Case Summary number: BMI 36; Time to booking= 11 days; booking to attendance= 1 month; Total time to help-seeking= 41 days

Experience of the Menopause: "Mickledy-pickeldy" journey through menopause. Confusion as to what stage of menopause she's in as she feels she should be post menopause or menopausal by now, but was told earlier she was peri-menopasal (unclear of definition).

Experience of PMB: Bleeding came in cycles until it became a constant and she was bleeding more often than not. Bleeding had become the norm and relief was short lived. It was more than just a period. Bleeding began to interfere with daily life and responsibilities, and she was fearful that the bleeding would be exposed in social situations. She felt unprotected outside the home.

Making sense of PMB: Making sense of PMB was done along with the attempt to make a link with additional symptoms of sickness (flu like symptoms and pain) experienced, despite doctor stating these are unrelated. Symptom was experienced as severe, because it was NOT associated with symptoms of going through the menopause.

Reason(s) for delay: Bleeding became the norm. Every bleed feels like it could be the last. Finds it difficult to book a doctor's appointment (without having to wait).

Position: It is the patient's responsibility to demand care, although there is also a personal apprehension in accusing or confronting healthcare services with problems. She often minimises her own experience and symptoms as not that bad.

Process: The process of help seeking began with cyclical bleeding, which turned to a more constant state of bleeding. This became the norm, but was still acknowledged as not quite right. She felt that at some point she would stop bleeding and this would confirm that she was post-menopausal (the stopping), but when she didn't and the bleeding kept on going the interference with daily life and the desire to make it stop brought her in to seek help.

Experience of help-seeking: Felt welcomed in clinic by friendly reception staff and lady doctor who listened to symptoms without instilling fear. Difficulty opening up to people about body issues (private, feel stupid because you don't know what's going on in your own body), and there is an expectation that on must open up to healthcare professionals.

Experience after help-seeking: **"***still a bit up in the air* ". "D*on't feel like I've been able to close the book on that bit"*. The questions remain unanswered as the results of secondary care tests were unclear or undelivered. The search continues (for an explanation for her bodily experience). Symptoms continue despite seeking help.

Previous help-seeking experiences: Previous negative experience with male doctor where she felt judged and dismissive of symptoms.

Reasons for seeking help: Reached the tipping point, symptoms had persisted too long and she was fed up and in pain) ("The penny dropped"). Sickness was severe and symptoms became unbearable ("head was going to explode").

Knowledge of Gynae cancer/menopause: Bleeding after menopause is not right; Menopause means no more bleeding. Weight affects health, but not gynaecological issues (of bleeding).

Researcher Reflection: She had a strong desire to be prepared for her interview and found it difficult to recall dates of help-seeking (Symptoms recognition and appointments).

Evidence for Themes

The ambiguous enmeshment of PMB and menopause: Uncertain ambiguity distinguishes the processes of menopause and PMB as a process of ambiguity that keeps resurfacing, hanging on and that is never resolved.

The shock of a bleed (after months without)
"Yea it was just lovely not having to think, 'Oh have I got anything? Have I got to wear something?' You know, (sigh). "

"I hadn't had a period in quite some time, erm, I couldn't work out whether it was a year, slightly under, slightly over… Um, well it was a bit of a shock, because I wasn't expecting anything,"…

"I might have gone for months and months and months and had a weeks worth, and then months and months and months and then you know, nothing for- I'm pretty certain it was about a year. And then BANG that happened, and it was heavy. And as I say, I'd never gone like so many weeks with it constantly like that."

No-one has the answers
"Yea, because I'm terrible, but there's so many people saying, "if you've got a label for something- If you can put a label on it, you know what you're dealing with"."

The unknown vs. the known
"As I say, it's a bit like it's [my period] reversed it's role. Normally you'd have so many weeks off and a week's period, so many weeks off, and it's like it's swapped."

The paradox of knowing
…
Searching for a cause
"I had *really* high temperature spikes to the point where my head felt like it was going to explode, and it wasn't just, 'oh I'm having a granny', you know the heat and the not feel to well. It really knocked me for sick. And then-and then after that's when I came on."

Still up in the air/ Book remains open
"Erm, so really I feel a bit like- still a bit up in the air. I-I know that they took a lining sample and that appeared to be okay. There was a growth or whatever, but they're not dually worried

about that. But that-that's as far as I am. So I don't feel like I've been able to close the book on that bit."

"I think from a person's point of view that's experienced the journey I don't feel like I've got an answer at the end of it."

"And unfortunately it's all come back to square one now. However, I've been told that there's nothing horribly wrong down there so. And then you kind of just have to remind yourself that perhaps this will just carry on for as long as it wants to carry on."

The conflict with severity
"At the time I thought, 'Oh that's it. Finished and done', but it came back again."

Weight and the uncertain risk
"Erm no I'm not sure that my weight has had a causing of the problem or an adverse affect on what's going on, but erm, obviously you've mentioned body image"

The chaotic body: Embodied Symptoms or a chaotic nature because of unpredictable experience of menopause and PMB. There are a set of embodied issues that are involved in the process of help-seeking for PMB. You can't take them out of the aging process, the weight-struggle, or the hatred of their body. This is all part of the chaotic body.

Shared vs. unique experience
"Erm yea I'd talked to my sister. Erm and she had been telling me to, "well, get yourself to the doctor's, get yourself to the doctor's". Because she has actually had problems, always, erm through her life"

Exposing the chaotic body (e.g. weight gain, hot flushes, bleeding)
"I couldn't do as much as I wanted to do, and then I had to keep nipping back in and out of the house, and when you're somewhere strange- rather than your own home you-you've got to be protected don't you?"

The internal hatred and mistrust
"I haven't got a very good body image so.

The catch-22 of weight-loss and health
"And of course the thing is you've got to kind of open up to people haven't you? You know, erm but I have been trying to lose weight and I've lost about half a stone, erm but yea (laugh)."

The penny dropped: What is it that makes women think something isn't right here and to seek help.

Relief as short lived
"Well I assumed I was [post-menopausal] anyway, because I-I'd been going through it for a number of years where it's been like months and months and months and then I'd have a

couple of days, and then it'd be months and months and months again, and so- I mean this has been going of for probably about 8-8 years."

"I-I think I remember having about a week thinking, '(gasp) this is nice- no period',

The penny dropped (i.e. the decision to seek help)
"Um, well it was a bit of a shock, because I wasn't expecting anything, cause I'm not having anything for such a while, and I thought, well they say you can. Erm so I was okay with that happening, but it didn't stop and I started to get worried."

[Sister was] yea, actively encouraging [me to seek help]... I think it, erm, the penny dropped for me when it had gone like- I think like maybe two months I think it was."

"I was down in Cambridge with my daughter and I kept having to go in and out, in and out the house possibly every hour, every couple of hours just to make sure that everything was okay still. I thought, 'no this isn't right'."

Interactions with healthcare for investigation toward treatment are uncomfortable at best and frightening, painful and intrusive at worst.

The feminine approach
Male doctor-"He said, " I don't think you're through the menopause, but there is a stage prior to the menopause". That's what he explained it to me, but anyway, we left it at that. And when this happened, erm then I thought, 'Right I'm going to go and see a lady doctor'. And luckily I saw a LOVELY lady doctor."

"Erm it-it-it probably wasn't, but how it felt was, "oh it's women's problems it will sort itself out. It's your age, this is what you have to expect". He probably didn't say that, but that's how it felt it came across.

Female doctor- "Erm well she actively listened, and she obviously knew more than I did, and she was reassuring, you know, straight away, "Right we'll have these blood tests done, that blood test done". I says, "Look, I'm so tired all the while. I've had enough, dah dah dah", and you know, that kind of thing; " Right we'll test for this this and this". So erm she found out that my folic acid was a little low, erm, so it just felt like somebody was actively doing something for ME"

Doctors' actions are greater than the words they speak
"As I say she actively listened. I told her about everything and it didn't feel like it was going on deaf ears."

The necessary intrusion
"opening up into, you know, what is kind of a private side of your life. You think- you- not many people find it easy to talk about what's going on with your body and I think the worst thing is when YOU don't understand it. You feel a bit stupid as well… , so the worry about opening up to people was frightening."

WENDY Case Summary: BMI 54; Time to booking= 2 days; Booking to attendance= 0 days; Total time to help-seeking= 2 days

Experience of the Menopause: She believes menopause is defined by age and occurs after 40.

Experience of PMB: *"What's wrong with me now?"* Bleeding mimicked normal past periods with one difference (blackish colour). The bleeding lasted one week and included large clots. She hadn't bled for 3 years. She tried not to think about symptoms of bleeding, but it was unavoidable, *"I couldn't could I?"*

Making sense of PMB: PMB is explained as connected to her mental health problems and "fatness". The bleed was understood as the last bleed of the menopause. After this she probably wouldn't bleed again and then she'd be considered post-menopausal.

Reason(s) for delay: n/a

Position: Unclear/complex story of menopause not separated from her PMB experience. Potential causes of PMB are difficult to discuss retrospectively.

Experience of help-seeking: Sought help *"straight away"* (within two weeks) and was seen straight away by her requested female doctor whom she has a positive relationship with and whom she visits regularly for mental and physical health problems. No examination was conducted at GP "*If you're bleeding they don't examine you"*.
Received social support from friends and children, but didn't inform children of PMB because she didn't want them to worry before she knew what was wrong (not until after help-seeking). What is not yet known is confusing and thus is not be shared with family. Doctor reassured her that everything was fine without explanation, but what does that mean?

Experience after help-seeking: Questions remain unanswered (why did I bleed?) *"Doctor's said everything is fine, because they found nothing at all.* Secondary care investigation involves unpleasant examination *"they shove it in ya"*.

Previous help-seeking experiences: Doctor advised for weight-loss and prescribed medication. She has never felt judged by her female GP. She experienced a negative had a painful examination with a previous male doctor, which reminded her of sexual assault from father as a child.

Reasons for seeking help: Recognition of abnormality raises concern. Knew **"***I shouldn't be going through this so there must be something wrong"* and the fear of cancer motivated her undergo the examination despite physical and psychological discomfort. Comorbid illness (diabetes and mental illness) sped up time to help-seeking and help received, because she was used to frequent visits.

Knowledge of Gynae cancer/menopause: She feels she's too old to bleed and that bleeding has something to do with her *"fatness"*.

Researcher Reflection: There is a difficulty in recalling dates of appointments and symptoms, and the story of her menopause was unclear and difficult to understand (enmeshed with the experience of PMB). It also appears that she has a desire to share her story of mental illness rather than her bleeding

It seemed important that researcher knows she is doing things to improve her health and weight as she often listed off the health behaviours she does to try to lose weight (swimming, running, walking).

Difficulty understanding the thoughts behind decision to seek help or recognition of symptoms and concerns.

Body Image: She prioritises other health problems over weight-loss, but there is still the desire to "*not get bigger"* .

Desire to live for kids inspire weight-loss or avoidance of weight gain and help-seeking behaviour. She has experienced negative weight-judgement and bullying from "the people on the street calling her "fat bastard". She's not judged by friends who help her stand up against the bullying, she "*get's blazed for it by other people though". Still she w*orries and cries about her weight when she's on her own.

She has been unsuccessful at previous attempts to lose weight.

Evidence for themes

The ambiguous enmeshment of PMB and menopause:

The shock of a bleed (after months without)

I came on, and I used to come on every month, but now because I've stopped- and after a long time I came on again, that's why I got worried. I thought, 'why am I coming back on again? I shouldn't be coming back on again.' Cause I'm 50 now anyway.

"Because I was- I thought there was something wrong with me, because the blood was like black…"

"I don't want it to come back on neither. It's not nice. Don't like it… All my clothes gets dirty. When I was young I used to come on really heavy. When I was young."

No-one has the answers

"What's happening to me?"

"They said that everything was fine, because I-they found nothing at all. They said eh everything's okay in there."

And yet, "I can't understand that why I came back on after three years… I shouldn't be coming on."

The unknown vs. the known

"Because I'm 50 years old and I shouldn't be coming on."

The paradox of knowing

"When I came here was- I got scared. I was thinking, 'what's gonna happen to me?'

"the next day I was at the doctors asking the doctor, "what's wrong with me".

"It's all right. I was worried when I first went in. Cause I don't want it. I told them I don't want it. They said okay, and I just got over it."

Searching for a cause
"Could have had anything, but this, they said was all right."

"But I didn't know what it was at first. Then I went to my GP. My GP said that yea, they referred me here to have it checked out."

"When you start thinking a lot then you start getting ill. Then you start to say, "oh, what's wrong now? Might be something wrong with me."

Still up in the air/ Book remains open
"They said that everything was fine, because I-they found nothing at all. They said eh everything's okay in there."

And yet, "I can't understand that why I came back on after three years… I shouldn't be coming on."

The conflict with severity

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Weight and the uncertain risk

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The chaotic body:

Shared vs. unique experience
"I said [to friend], "yea I'm bleeding. That's why I have to go[…] I said it was for a week. She said, "that long?"

Exposing the chaotic body (e.g. weight gain, hot flushes, bleeding)
"When that happened to me I booked with my GP, because I couldn't sit down and that was keep on coming."

The internal hatred and mistrust
"I don't like it when I'm big. You know like when people say to me- swearing at me and saying things."

"Then I stay in my house. Since I've known P2F and [friend] I go around to their house a lot and I don't stay home that much, because I know that I've got somebody. It used to be when I would get out of the house I used to get abused and blazed and all that before, and now I don't get none of that. Before I used to get a lot of swearing."

The catch-22 of weight-loss and health
"I've been taking that medication every day. And that could be putting on my weight. Sometimes I worry about myself. I don't want to get more bigger."

“My doctor sent me to Heartlands Hospital, because I stopped breathing 52 times. Yea. I’m on a sleep apnoea machine.”

“I walk slowly. Don’t walk fast […] I have arthritis in my feet so that’s why.”

The penny dropped

Relief as short lived

“Exception to the rule: “After that [a week of bleeding], touch wood, I haven’t come on. I haven’t come back on at all[…]I get out of breath if I don’t have my machine.[..]”

The penny dropped (i.e. the decision to seek help)

“When that happened to me I booked with my GP, because I couldn’t sit down and that was keep on coming.”

Interactions with healthcare for investigation toward treatment are uncomfortable at best and frightening, painful and intrusive at worst.

The feminine approach

“I went down to go to my doctors. I go to the lady doctor. I go to the lady doctor.”

“Because when I go in and they’re really kind to you and they’re really lovely to you. They hug you. They talk to ya. It’s really good. My-my doctors really good.”

“not nice. Cause this is the first time a man doctor done it.”

Doctors’ actions are greater than the words they speak

…

The necessary intrusion

“[The examination] It wasn’t nice… It hurts… when they shove it in ya.”

P2: They put that metal thing in to make it wide.
P2F: Yea, but remember you weren’t relaxing as they kept telling ya to relax.
P2: I know I can’t do it. I can’t.
“P2: It’s all right. I was worried when I first went in. Cause I don’t want it. I told them I don’t want it. They said okay, and I just got over it.
R: Okay, so you managed to get through it. What made it so that you were able to go through it?
P2: Do you know, I don’t want cancer.”

JUNE Case Summary: BMI 37; Time to booking= 30 days; Booking to attendance= 7 days; Total time to help-seeking= 37 days

Experience of the Menopause: "Didn't have much problem going through the menopause" No bleeding since 46. After menopause believed there should be no more problems: "you sort of think that's the end of it […] you're not going to have any more problems with it".

Experience of PMB: Holiday was interrupted by bleeding when she first noticed it on the toilet. Looked up symptoms on the Internet (forum) but felt they were talking about bleeding during the menopause and this didn't relate to her. She only told her husband about the bleed although she was more worried than she let on. She experienced the symptoms as silent- it did not cause her any pain or discomfort. Each bleed was experience as the last bleed, "You think it might be just a one off." Symptoms weren't accompanied by any pain or discomfort, "It was insignificant". "I couldn't rationalise into in my head as being serious."
She bled for one month before booking an appointment.

Making sense of PMB: "where's that coming from thinking, have I scratched myself?" "I couldn't quite put my finger on why it was happening", because hadn't got any knowledge or experience of it happening to anybody else. She didn't think cancer could be a cause until she looked it up on the Internet.

Reason(s) for delay: The severity of the symptoms didn't make sense, "I feel perfectly well. I don't feel as though there is anything wrong with me [..] Which is sort of weird because you're head's saying, 'you really should get that sorted out, but your body's thinking, 'Oh I feel okay!"(Doesn't signify severity)". "if I'd have felt unwell as well as spotting I would have been a bit more worried". Illness is a strange concept to her, because family hasn't' been ill. Illness "wasn't in my sphere of acknowledgment"
Furthermore she didn't see the point in wasting the doctor's time "if I know that I'm okay, sort myself out with a few tablets or rest, or whatever." "they've got enough people to see that are *really* ill, and possibly I'm not as ill as they are.

Position: It was important for her to be able to accurately recall dates and be prepared for interview. She takes the blame for painful examinations by suggesting that "possibly was just tensing at the same time". She prefers a lady doctor to a male doctor for gynaecological problems: "I just thought I'm more comfortable with a lady doctor." "Old fashioned I suppose"-; "To be with somebody that understands what you're going through. Because she's *fairly educated* she feels she should have known something about post-menopausal bleeding

Process: Ignored smear test letters for two years and when experienced PMB she knew something was not right but because she didn't feel unwell she didn't experience it as severe enough to seek help, until she looked on the Internet and it mentioned cancer. She then booked an appointment for a smear test and was advised to book an appointment with the doctor (which took one week because she requested a lady doctor). After seeing the female doctor she was given a referral for the PMB clinic.

Experience of help-seeking: Smear test was "quite painful". Booking an appointment took one week to get a lady doctor's appointment that fit into her schedule had to book around work commitments. She does not have a regular doctor and see's someone new each time, but the reception is always very efficient and welcoming. Doctor was a good doctor, she provided information without “scare mongering” explained that the bleeding could be a symptom of cancer and the lining of the womb needed to be checked. The doctor also told her she needs to be visiting the doctor more regularly. Referral was “rather quick”.

Experience after help-seeking: Her positive experience made her wonder why people dislike going to the hospital, but in comparison to other negative hospital experiences she’s heard about from friends, she understood why.

Previous help-seeking experiences: “I got told off actually [for not coming in for smear test..] about two years ago. They said, ‘ I haven’t seen you for 6 years’. I said, ‘well that’s because I wasn’t ill for 6 years’. – Reason for visit was for swollen ankle.

Reasons for seeking help: Thinking about a recent experience of a friend who felt “perfectly well, or thought she was, and had to go to the hospital for that”, made her think of exceptions to the understanding that if you’re unwell you’ll feel unwell, “because just because you’re feeling okay, don’t mean everything’s okay”. Symptom’s are concerning because “it’s been 15 years since I’ve had my period and it carried on happening which affirmed that it wasn’t just a “one-off”
If information about PMB was more readily available she would have sought help sooner.

Knowledge of Gynae cancer/menopause: “I *had* to look up on the Internet to see how common it was”, and the answer was surprising”**.** Knowledge about causes come from family history with mum having had fibroids. *We* know a lot about menopause, we don’t know about the things that happen afterwards.”
Knowledge of obesity risks: “being overweight does actually give you more chances of things (diseases?)”, personalises her risk by saying “and I’m not particular skinny.”

Researcher Reflection: Significant life events (holidays and birthdays) helped to recollect dates. Husband provided perspective on her attitude against seeing doctor for illnesses.

Body Image: She has never been skinny, but “I’m probably the heaviest now than I’ve ever been”

Evidence for themes

<u>The ambiguous enmeshment of PMB and menopause:</u>

The shock of a bleed (after months without)
“…but it-it was the vagina so, yea, that was a bit worrying, because it’s 15 years since I’ve had my period, so you know, I didn’t know- this shouldn’t be happening.”

No-one has the answers
“I was a bit more worried about it, because I wasn’t aware that this sort of thing happened. It-nobody I knew had ever mentioned it, so I thought, ‘Oh this is odd’”

The unknown vs. the known

“Yea, and when I’d been to the doctor’s I mentioned it to the women at work, and actually they didn’t know much about it either, and I think cause one or two where in there 40s, 50s. So although we know a lot about the menopause we don’t know about the things that happen afterwards. You sort of think that’s the end of it, you know, you’re not going to have any more problems with it.“

“I had to look it up on the Internet to see how common it was and I was quite surprised.”

The paradox of knowing

..

Searching for a cause

“I thought it might be a cyst or a polyp or something, because my mum had fibroids many years ago when she was expecting my brother actually. She was in her 30s and I thought, ‘well maybe it’s something like that if it’s a family sort of inherited thing.”

“I thought, ‘ where’s that coming from’ thinking, ‘have I scratched myself? What?’

“Two or three [times visited websites], because one of the ones- one of the sites I found, people that had it were still going through the menopause, so I thought, ‘well that doesn’t really apply to me’. So I did have another search to see if I could find sort of- but there wasn’t a lot actually about people that had gone totally through the menopause for several years and then had the symptoms.”

Still up in the air/ Book remains open

…

The conflict with severity

“I feel perfectly well. I don’t feel as though there is anything wrong with me [..] Which is sort of weird because you’re head’s saying, ‘you really should get that sorted out, but your body’s thinking, ‘Oh I feel okay! […] I think if I’d have felt unwell as well as spotting I would have been a bit more worried, but the fact that I felt perfectly well, and that this was just a bit odd.”

“If I know that I’m okay, sort myself out with a few tablets or rest, or whatever…they’ve got enough people to see that are *really* ill, and possibly I’m not as ill as they are.”

Weight and the uncertain risk

P3: Yea, because you do see a lot of things in press now that being overweight does actually give you more chances of things and I’m not particularly skinny. I’ve never been skinny, but I’m probably the heaviest now than I’ve ever been.
R: Okay. Have you thought about how, erm being overweight would cause bleeding at all?
P3: No. No, I couldn’t work that one out.

The chaotic body:

Shared vs. unique experience

“We know a lot about menopause, we don’t know about the things that happen afterwards.”

“My family doesn’t have a history of illness or operations or things like that. It wasn’t in my sphere of acknowledgement if you know what I mean, and of course- so it did worry me, unusual.”

Exposing the chaotic body (e.g. weight gain, hot flushes, bleeding)

“having any spotting at all and then quite a bit of spotting, and then it would stop again. So[…]it was just, yea all over the place.”

The internal hatred and mistrust

….

The catch-22 of weight-loss and health

“I’m probably the heaviest now than I’ve ever been”

The penny dropped

Relief as short lived

“it’s been 15 years since I’ve had my period and it carried on happening which affirmed that it wasn’t just a “one-off”

“Yea, because I wasn’t getting it all the time. It was intermittent as well, because I could go 2 or 3 days without having any spotting at all and then quite a bit of spotting, and then it would stop again.”

The penny dropped (i.e. the decision to seek help)

*“*You know you think it might be just a one-off, but then it carried on happening so I thought, okay this isn’t right. “

“It’s got to have been about 6 weeks before I thought, ‘well this must be serious, because it’s not going away’.”

Interactions with healthcare for investigation toward treatment are uncomfortable at best and frightening, painful and intrusive at worst.

The feminine approach

“I just thought I’m more comfortable with a lady doctor […] Old fashioned I suppose”

“Erm she sort of took me through a few what-what it could be. She did mention that it could be cancer, but it could be the lining of the womb so it needed to be checked out. Yes.”

“Yea, just to be with somebody that understands what your going through (laugh).”

Doctors’ actions are greater than the words they speak

“Well she didn’t seem to think that-… Well she didn’t scare monger, let’s put it that way. She was very matter of a fact when she was talking to me and asking me- a bit like I was having a conversation. It was very comfortable, very *informative* actually, because I hadn’t realised how common it was. “

The necessary intrusion

"She stopped, because it was getting too uncomfortable, and that's when she said, yes you really should see a doctor. So I booked the appointment with the doctor, and actually the doctor managed to be able to do the examination without it being too painful."

CAROL Case Summary: BMI: 62; Time to booking= 305 days; booking to attendance= 0 days; Total time to help-seeking= 305 days

Experience of the Menopause: She shared in her experience of menopause with most of the female members in her family, “because we were all more or less on the same path”. Menopause is when you’re still having your period; she doesn’t seem to fit the definition of menopausal (confusing). Unsure of what it means to be menopausal**.** Thrush symptom replaced the period. Thrush is her “body clearing out what was in the body during childbearing age and due to hormones during menopause”. Consistency of symptoms starts to wear you down

Experience of PMB: The initial bleed was just a “*show of blood” (brief and once*) and she does not consider it an *actual* bleed. She noticed it when wiping. Time since last period makes a bleeding now abnormal, but then the pattern of recurrent bleeding symptoms creates normalcy. Symptoms continue and are on-going.

Making sense of PMB: She was unsure if she was menopausal because her bodily experience of symptom doesn’t match her definition of menopausal OR post-menopausal, because she believes she shouldn’t be bleeding either way. She believes that PMB was caused by psychological stress.

Reason(s) for delay: Was not concerned about PMB.

Position: Is it the patients’ responsibility to find out the answers by asking their doctor rather than waiting for the answers to be given to them by the doctors, and attending preventative screenings is important.

Process: Experienced a slight bleed and was not concerned. Because she had a cervical screening booked a couple of days after, she attended and mentioned it to her doctor (under the encouragement of her husband). She was referred to PMB clinic who told her she was still going through the menopause. Her bleed then returned after secondary care visit.

Experience of help-seeking: Convenient help-seeking at pre-booked screening appointment and mentioned bleeding to nurses. Communications about her symptoms between nurses and doctors in front of her raises concerns and was frightening. The concern didn’t exist until she witnessed the healthcare professionals’ concern. Witnessing their concern had a greater impact than the comforting words they spoke, stating not to worry, but that they want to refer her to a specialist to be safe “their actions were greater than the words they spoke”. HCP concern brought detrimental thinking “I wonder if I’ve got cancer”.
When she attended the PMB clinic she experienced a Paradox of knowing: Wanting to know, but not wanting to know that something is wrong, because experiences future dread about what she would do with familial and financial responsibilities if things were medically “dreadfully wrong”. She was “walking out with the weight of the world on my shoulders”. The examination was uncomfortable, “I’d just been clamped open, BUT STILL”, I didn’t mind it, because wanted answers. She received the results of test that her bleeding was caused be her not yet being through the menopause.

Experience after help-seeking: She was given "menopause" as the reason for her bleed, but if she's not yet through the menopause then how much longer will this last? Doctors told her probably still going through the menopause. When does the tunnel end, "They've told me not to worry about it; so I'm not worried, but how long does that go on for?"

Previous help-seeking experiences: Last visit to doctor was for common comorbid concern (swelling of ankles with diabetes). Her regular comorbidity GP visits builds strong relationship with nurses.

Reasons for seeking help: The wanting to know is stronger than not wanting/ fear of knowing.

Knowledge of Gynae cancer/menopause:
Knowledge of menopause: She knows that menopause is a change in hormones, and that if you've had a proper bleed a year ago means no longer going through the menopause.
Knowledge of obesity as a risk factor for "diabetes, heart attack (the normal ones) and all the ones that can kill ya"
Knowledge of gynaecological cancer: Believes it can't kill you

Researcher Reflection: It's difficult to remember actual dates of the help-seeking process, but recalling personal events (birthdays, holidays) help to recollect dates. There was an acknowledgement of the age gap by the participant. It was difficult to raise the issue about body image and researcher found that the participant responses to weight related questions were short and dismissive.

Body Image: Weight/size does not play a role in the decision or experience of seeking help because, "it's all necessary isn't it".

Evidence for themes

The ambiguous enmeshment of PMB and menopause:

The shock of a bleed (after months without)
"Yea. It wasn't actually a bleed. It was almost like a show. So- so it wasn't an actual bleed. It was just that I hadn't had anything for quite a few months."

No-one has the answers
"They've told me not to worry about it; so I'm not worried, but how long does that go on for?"

"I suppose at the end of the day I got the letter to say, you know, nothing was-nothing was wrong, but you still haven't gone through the menopause yet, you know. You know, but they didn't say anything about why I'm just trickling or not even just trickling but spotting. There's no answers to that. It's just that, 'you've not gone through the change yet'. But I'm not having a proper period as such […] it's definitely not regular. I don't suppose that's all part of the course…?"

The unknown vs. the known

"I didn't actually think it was anything to be- Until they, well until they went into, you know, all actions. Before they'd phoned the doctor and get the clinic and stuff I didn't think anything of it."

"Answers. I just wanted to know what was wrong with me […] Yea, and then I probably would have had some questions, but I hadn't planned anything, because I didn't know what was going to go on."

The paradox of knowing
"Well I wanted to know. I think-I think I wanted to know. I didn't want to know, but I wanted to know. I wanted to know that there was something physically wrong? I don't know-I don't know. I *did* want to know, and I just wanted, yea, I just wanted to know. That's why I made the decision to come to the clinic and mmm. I did."

"I was a bit nervous, yea. A bit nervous, yea, thinking I was going to walk out with the weight of the world on my shoulders."

"I don't know, I had lots of thoughts didn't I? What was I gonna do? How was I gonna tell people what was going on, and you know, what was gonna happen? How I was gonna pay the bills. You know, I was thinking like all sorts of things, all sorts of things."

"But then after hearing that, "actually we've got a concern because you've bled". It was like, 'Oh shit. That's connected to that and that's connected to that'"

Searching for a cause
Thrush & bleeding: "I just thought that with my hormones changing and everything else it was just coming back[…] It was unusual now, but I just assumed it was because my body was changing."

"I was thinking like, I was thinking detrimental really, "I wonder if I've got cancer". That sort of thought."

"It might-I'm thinking that it might have something to do with psychological or- I don't know. I don't know."

Still up in the air/ Book remains open
"What they said was that they didn't think that erm I'd started the menopause yet, because I'm still having bleeds. Erm, and they-what they- the neck of my womb was still too thin or something, or too thick or whatever. So that was a sign that I hadn't started the menopause. […] Well it's supposed to mean that I'm still supposed to be having my periods, but I don't."

"My mind's been rested assured in that it's nothing serious, but still I haven't…I've not been given any hard and fast answers on why it's happening or what I should be looking out for and if it's mixed with, "you need to probably come back to us", you know, I'm sort of left at, "okay and you haven't gone through the menopause so that's kind of normal that you should be bleeding". And as I said before, how long is this going to go on? And, do you know what I mean? I've had no indication as to…"

The conflict with severity
"Yea. It wasn't actually a bleed. It was almost like a show. So- so it wasn't an actual bleed. It was just that I hadn't had anything for quite a few months."

"I was concerned only because it had been so long since I had seen any bleeding, but I wasn't- I was concerned, but I wasn't."

Weight and the uncertain risk
R: What do you know about weight and risk for diseases?
P4: Oh, well the normal ones like erm diabetes and erm, heart attack and stuff like that. I've heard those ones, but nothing else really, and all the ones that can kill ya (laugh).

The chaotic body:

Shared vs. unique experience
"I started noticing the change was probably back in October, November last year when I probably thought, because my sisters were going through it I probably thought I was going through it. So I just assumed that everything that happened, because we were all more or less on the same path. Like, "This has happened"- "Oh yes I remember this happened" and then the other one would say, "Nah this has happened" and I would say, "oh yea I remember that's happened, because there's only like two years between us all. So we were like- and my mum said that she went through when she was like in her 50s and whatever, so we just assumed that, you know, everyone was following everyone down. So even my younger sister's gone through it before it."

Exposing the chaotic body (e.g. weight gain, hot flushes, bleeding)
"Well it's supposed to mean that I'm still supposed to be having my periods, but I don't."

The internal hatred and mistrust
"Well it's supposed to mean that I'm still supposed to be having my periods, but I don't."

The catch-22 of weight-loss and health
…

The penny dropped

Relief as short lived
"Yea. It wasn't actually a bleed. It was almost like a show. So- so it wasn't an actual bleed. It was just that I hadn't had anything for quite a few months."

"It was- It was gone as quick as it came to be honest."

The penny dropped (i.e. the decision to seek help)
"By that time I was worried, thinking I should have been over this by now, and it was as far as I'm aware a year, so I should have been over that bleeding by now. So I took the bleeding to be something else you see, something a bit more serious at that point."

Interactions with healthcare for investigation toward treatment are uncomfortable at best and frightening, painful and intrusive at worst.

The feminine approach

“For my smear test. And there’s like the regular four nurses and it’s like, you know, well I do know them all, because I go there for asthma and my iron and blood tests and so I see them all the time”

“Well constantly talking about something completely different (laugh) was good (laugh). Yea, and telling you what they’re going to do, why they’re going to do it. So all that’s sort of said before you actually lie down, so you know what they’re going to do and everything else. By the time you get to that point we’re talking about something completely different- what happened with, I don’t know, Grandchildren or something. So it’s all like over and done with by the time you’ve finished having the consult so.”

Doctors’ actions are greater than the words they speak

“I think they tried to explain to me as plainly as possible that it was nothing to worry about, but at the end of the day you were still you’re still thinking, ‘well actually’. But I think that the way that things happened it was like, “Oh, that’s happened, I need to phone the doctor” and then they phone the doctor and the doctor said, “Refer to the clinic”, and it was like I was like just watching all this happening and thinking, ‘I wonder if that’s like something serious like’ sort of thing. So, I went away thinking not really about what they said, but more about what I was thinking about and that it might be something serious and I’m meant to get it sorted.”

The necessary intrusion

“I’d just been clamped open, BUT STILL[…] It’s all necessary isn’t it.”

“It’s always feels awkward, but it’s all right. It’s all right”

MICHELLE Case Summary: BMI: 39; Time to booking= 3 days; booking to attendance: 0 days; Total time to help-seeking= 3 days

Key Descriptive: PMB is confirmation that her body is breaking down. A series of multiple shocks one after the other, with no ending in sight (diagnosis of breast cancer, treatment, menopause, PMB).

Experience of the Menopause: Too young to be going through the menopause. A unique experience unlike most, where she was confronted with the experience abruptly and was in shock. Early menopausal experience was a side-effect of breast cancer treatment (Tamoxifen). Her first experience of a hot flush was met with fear and panic; "I thought I was having a heart attack". A hot flush is the hottest fire burning up through the body from the inside out, like a severe flu. Hot flushes are socially embarrassing, because the menopause and a woman's older age are made public and create an inescapable situation. Women in the menopause seen as old and "decrepit." Menopause means she can no longer enjoy the things she used to (e.g. is no longer able to have children) and not being able to have children is being closer to death.

Experience of PMB: The experience of PMB was part of an overwhelming year-long struggle with breast cancer diagnosis and treatment, and was experienced as a negative side-effect of Tamoxifen cancer treatment "Cancer struggle is being on a treadmill without an end point and getting nowhere". She felt "Panic because you think it's cancer. I did think straight away that, 'this is not right. I'm bleeding on the Tamoxifen." The bleed was different from a normal period, more severe with discharge, big clots of blood, and painful. It was unpredictable and she needed protection when she left the house. The was a frightening experience and reminded her of a previous miscarriage, a "Dragging down and feeling the pull feeling".
The experience of PMB came with a series of continuous shocks: of help-seeking, investigations, diagnosis, treatments and complications. The problem is not the PMB it's the breast cancer "I blame the cancer. It's ruined everything."

Making sense of PMB: PMB was confirmation that her body was breaking down and that the cancer had moved to her lower region from her breast, and her lack of control or inability to stop it. "You know, there's something wrong. You know, you think, 'No way is that right'. "Everything is against me". Thinking about and trying to make sense of the PMB makes things more difficult, the symptom doesn't have to bother you, but the thoughts make you panic. Thickening of the womb caused the bleed and is a sign of cancer caused by breast cancer treatment Tamoxifen.

Reason(s) for delay: There are none.

Position:
The supportive husband- The supportive husband tries to help by minimising her problems and acknowledges the difficulty and severity of her experience; Emotional response to how she felt about her body during the time prior to the bleeding.
An emotional response to the body: experience of the body during bleeding: "I hated it".
Personal unique experience- She is the only one to go through her cancer experience (unique only to her), and "most women don't have cancer when they have PMB"

Beliefs of help-seeking- Seeking help is “no biggie” “so just get it checked”

Process: Series of medical problems/events that seemed to come on one after the next and it continues to feel like there is no end to it (with the diagnosis of breast cancer, depression, complications during surgery and recovery, and then bleeding and complication with results). The impact of these events has lead her to develop a pessimism regarding her health in that any abnormality now means cancer and she is coming closer and closer to death, feeling that there is not much more to look forward to.

Experience of help-seeking: Prepared for doctors to say the cancer had spread from her breast, “oh no not again”. Thinking ahead about what will need to be done to remove the risk is the helping and hurting risk-reduction trade-off of seeking help and receiving treatment. By exposing one’s body to medicine you give up control and ownership; Uncertainty of investigation results. Furthermore, there is a removal of choice in what happens to her body, the team of “doctor’s decide what to do next”.

Experience after help-seeking: Doctors were unable to give her a definitive yes or no and she left unsure. Question about if she was menopausal left answered.
“My feelings, my body was going- just falling apart; Can no longer trust or count on the body to function properly.”

Previous help-seeking experiences: A recent frequency of examinations makes examination the norm, however, past experience of seeking help for serious gynaecological concerns (ectopic & miscarriage) and for breast cancer makes the experience of help-seeking petrifying. “You lose everything. You lose your dignity… Nothing’s private anymore” “It doesn’t feel like my life… My body don’t belong to me anymore”

Reasons for seeking help: The knowledge that she shouldn’t be bleeding brought her in to seek help. Body awareness to know when something is wrong and knows how to seek help.

Knowledge of Gynae cancer/menopause: She believes that losing weight might help cancer to not return, however, a healthy-lifestyle is more beneficial than weight-loss. Body aware is gained from previous health experiences: an awareness of her body. Knowledge that the thickening of the womb caused the bleed and is a sign of cancer caused by breast cancer treatment Tamoxifen

Researcher Reflection: Unclear if she’s still undergoing treatment for breast cancer though she uses past tense to describe, “I’ve had erm, breast cancer”.
The struggle and lack of control continues to the present.
It seemed important to her that the researcher knows that she’s doing things to better her health.
The role of the supportive husband is sometimes invisible/ forgotten “he is lost”.

Body Image: *The catch-22 of weight-loss and health*- Breast cancer treatment makes weight-loss difficult and the prevention of cancer is made difficult by side-effects of treatment medication. Furthermore, comorbid illness (arthritis) make healthy-lifestyle changes (exercise) difficult.

Body image issues are nothing new, but it's worse with the loss of ownership. "I just hate it. I hate my weight. I hate how I look. I got scars."

Evidence for themes:

The ambiguous enmeshment of PMB and menopause:

The shock of a bleed (after months without)

"Yea, like a discharge and it was like erm big clots; there was a lot of blood. LOTS of blood. Erm.. (sigh). Awful, just AWFULL pain, erm, irritability. You know, just like you would a period, but it was just- it was more severe than a period. […] Clots about that size [hold up fingers in the size of a golf ball] coming out you know. Like liver.

"It was just- cause I have, I've had a miscarriage in the past and I've- it felt like a miscarriage which, you know like the dragging down and the feeling pull- the pull feeling you know. That's how it felt, like I was having a miscarriage, but obviously I wasn't… He's been done (laugh) [pointing over to husband]."

"One day I found tingling up here and I thought, 'What? What's this?' You know I couldn't understand it. I thought, you know I was having a heart attack or-or, I don't know what I thought. I just thought- I panicked. I had a panic attack, because I didn't know what this was, because I'd never experienced anything that powerful before."

No-one has the answers

"Pre-menopausal, yea. So that's before menopause. So what's the difference as menopause or pre-menopausal."

The unknown vs. the known

"I shouldn't be bleeding if I'm in the… on the Tamoxifen so my uterus has gone from 3 mil to 15 mil thick since I've been on the Tamoxifen, which is may last year."
"You know, there's something wrong. You know, you think, 'No way is that right'.

"People saying you know, "It's come back", "It's gone somewhere else, or" You know, there's always a risk. And this is what they're thinking here is that the cancer has come back. Well it's gone down below now. That's why they're doing all the procedures, because of it being like, thickened"

The paradox of knowing

"Panic because you think it's cancer. I did think straight away that, 'this is not right. I'm bleeding on the Tamoxifen. It's cancer, and I just thought, ' oh no not again'. You know, and I was thinking, you know, far into the future., "Oh God it's going to be radio-therapy, I'm going to lose my hair and chemo and all that.' DO you know what I mean? I was just thinking the worst."

Searching for a cause

"Panic because you think it's cancer. I did think straight away that, 'this is not right. I'm bleeding on the Tamoxifen."

"It's just like, 'Well, what's going on'. You know, not knowing what's happening to your body. You know, it's just coming away and you think, 'OH God, what's this? Am I dying? Is it cancer?"

Still up in the air/ Book remains open
"I haven't had a break for, since March last year. I feel like I'm on a treadmill where it's just constantly on and on and on and there's no stop to it. And I thought that as soon as I get the cancer away that would be it. There would be no more. I could get on with my life. You know, try and do something with my life. But at the moment I feel stand still, at a stand still. I can't go forward. It's awful, you know, just "Can I finish with that doctor?", but no it's just the three. It's hard work."

The conflict with severity
"It was just- cause I have, I've had a miscarriage in the past and I've- it felt like a miscarriage which, you know like the dragging down and the feeling pull- the pull feeling you know. That's how it felt, like I was having a miscarriage, but obviously I wasn't… He's been done (laugh) [pointing over to husband]. You know, so it's not- it was just after being on the Tamoxifen."

Weight and the uncertain risk
P5: There's nothing nothing I can do. I can lose weight I suppose. But I have tried, haven't I. I've tried hard haven't I?"
R: Mmm. And losing weight, what would that do? How would that help?
P5: [long pause] I don't think it would. You know, I eat healthily. So I – you know, I do eat healthily, don't we [looking at husband]? […] So, I think that's the main thing, if you eat healthily. If you eat- you eat healthily then you know, that's a help. But other than that there's nothing you can do. There's nothing… Nothing. Is there? (laugh)

<u>The chaotic body:</u>

Shared vs. unique experience
"- it's vile and like- like I went straight into it. Like other people sort of- if they're not on the tamoxifen they gradually build up to it, because obviously they're going into the menopause gradually. I went in straight away. So it was like everything just went in, straight away (ppshhoow). "

"…most women don't have cancer when they have PMB"

"Yea, but it's different it's completely different to YOU going through it. ME going through it. You know and you speak to people, you hear of things."

Exposing the chaotic body (e.g. weight gain, hot flushes, bleeding)
"Erm, it's nothing that I've ever experienced before. It was like a real, I don't know… inner fire. You know it's just sort of like (whoorfff)[makes the noise of a roaring fire]. Really, Woaah! And it is, it's inside it's not I outside. It's in like in your body. You know like if you go on holiday, you're hot, you know and you can feel a hot heat on your body [pointing to her arms]. But this is inside and it's weird. A weird feeling of heat. Erm, like you're burning up

inside. You know when you've got like a severe flu. It's that heat. It's that heat and it's horrible. Really REALLY horrible"

"No, it's I was constantly wearing protection because it was like I didn't know where I was- I could just suddenly lose a clot, you know, and it was like, 'Oh my God what's this?'.

"Old, decrepit. Just a few words to, you know, I remember thinking when I was younger, women going through the menopause are like old. You know, erm… like their life's, over. Do you know what I mean? I can't really explain it. It's like they're looking at me and thinking, 'Oh God she's old and decrepit' (lauh). You know? To go through that- the change, there's no purpose anymore, purpose in life. It's a sign of getting old isn't it? DO you know what I mean?" […]Yea, it means that I don't feel old and decrepit, but other people who haven't been in the menopause, that's how they look at me, as being old and decrepit. Because I'm going through the menopause. You know, I'm getting hot flushes and because you can see that. You know, you can physically see it. You know what I mean?

The internal hatred and mistrust
"I just hate it. I hate my weight. I hate how I look. I've got scars. Scars across here [pointing to chest]. Erm, Just really hate it. I hate my body."

"I hated it. HATED what- I'd got no control. I-I've, my feelings, my body was going- just falling apart. It felt as though Ah, something else. You know, what else can go wrong? Your heart, cancer… You know. (Sigh) I'm getting a bit teary now [began to cry]. (Giggle)."

The catch-22 of weight-loss and health
"Cause I've got bad knees and feet. I've got erm problems with my heels as well you know, I've had operations on them."

"Severe arthritis. It's been blamed for a lot of things that- but, how can I put this? I try hard to lose weight. I TRY so hard. So, you know, I can't explain it. I can't explain it. Sorry… I suppose I blame myself. I blame myself for getting like this. But I do try and not to be like this if you know what I mean. It's the tablets [for breast cancer treatment][…] Because my sister, when she started on the tablet, what I'm on she ballooned. You know and it is hard isn't it."

"So that was one of the risks. It takes cancer away from there [pointing to breast], but could put it there [pointing to groin area]. (laugh)"

<u>The penny dropped</u>

Relief as short lived
"Dragging down and feeling the pull feeling"

The penny dropped (i.e. the decision to seek help)

"It was about two months after [starting Tamoxifen treatment] no about 6 weeks and I started bleeding and it was quite heavy and erm, big clots and awful awful. Pain was really bad."

“And like when I started seeing those big clots I thought, ‘OH my God’. You know, there’s something wrong. You know, you think, ‘No way is that right’. You know, even when you get your period you have little clots, you know. Normal- normal clots, but it was like pink, the blood was like fresh. It wasn’t like a period blood like red. This was pink and with the clots, so it was a lot lighter and I thought, ‘That’s not right. That’s not right at all’.

Interactions with healthcare for investigation toward treatment are uncomfortable at best and frightening, painful and intrusive at worst.

The feminine approach
“you know like when you have your smear it’s like undignified and so you go along and you have your smear and it’s a women, but it’s a male doctor so it would have been embarrassing having a male. And because I know the doctor so well, as well.”

Doctors’ actions are greater than the words they speak
…
The necessary intrusion
“My body don’t belong to me anymore. It belongs to- cause everyone’s seen it and everyone’s been there (laugh) and touching and- It just feels that- that you just don’t, ugh, just, you know, strip off your- you know everything just goes. Where before you’d say, oh get a bit upset about having to lie down and get an- examined, but now you just you- (laugh). Do you know? You just lose, you lose everything. You lose your dignity. You loose everything. Nothing’s private anymore. You know, your body’s not your own and it’s given up. It does give up.”

“So when he says, “Hop up on the couch and take your pants off”. You just do it, because it’s norm- the norm now. You know, so it was- going to the doctor’s didn’t bother me at all. I just went, but I think if it had happened 12 months ago or longer, you know it would have bothered me. It would have- I would have thought I can’t. You know, it’s too embarrassing, no no no no.”

SHARON Case Summary: BMI 46; Time to booking= 3 days; Booking to attendance= 3 days; Total time to help-seeking= 6 days

Experience of the Menopause: Confusion, no answers as to what is causing the symptoms (i.e. thyroid problem, menopause) or how long she'll be going through the menopause. A tunnel with no end in site (no one can say how far in or close to the end she is).

Experience of PMB: Sought help twice for PMB. First was an emergency thought to be due to Warfarin problem. Second was thought to be a problem with the Mirena coil (i.e. replacement).
Frightening, lack of control, socially embarrassing, something was seriously the matter (i.e. 11 days, heavy bleeding), unprepared (i.e. needed towels, underwear, shower curtains, avoided sitting, and made frequent visits to the toilet -every 5 minutes).

Experience of help-seeking: Initially thought it was an emergency Warfarin problem. History of cancer in the family and Google symptom search (says cancer) that encouraged her to seek help.
Discovered a different problem on second visit for PMB (contraceptive issue). Help-seeking is "taking the simple solution rather than continued suffering".

Position: Embodied experience, "It was pouring out of me", "made me feel horrible, dirty". Indicates her unique experience and does not claim to be an expert in the experience of PMB or menopause.

Process: "The" symptoms of menopause are expected (e.g. "the heat", "the skin") until the weight-gain. But weight is different. When the topic of weight emerges in the interview she expresses deep emotion (crying) in telling the experience of her inability to lose weight.

Experience after help-seeking: The questions remain unanswered. Didn't get what she came into the doctor for.

Researcher's reflection: Medication seemed to interfere with experience of menopause, confusing the experience.

Body image: Great emotion and frustration accompanies the experience of weight gain and the inability to loose weight after menopause.

Evidence for themes

<u>The ambiguous enmeshment of PMB and menopause:</u>

The shock of a bleed (after months without)
"So, erm I haven't had a lot of physical problems with the heat and stuff like that. I take Menopace which I find seems to help. It seems to – erm there's less hot flushes. There's less mood swings. Could all be in my head, but it's working it's working."

“And then when I had the big- first big bleed in the August, I didn’t know what that was. I’d had a Mirena coil for a lot of years and it was obviously less effective. It was never for contraceptive, it was for heavy periods that I had it.”

No-one has the answers
“I’ve had my blood tests done and that’s fine, but you just don’t know whether all or these things are all the menopause or all of that, or a bit of each. Or it’s just that one. I just don’t know. I do struggle a bit with confusion over why I feel like I do. Whether it’s the menopause or whether it’s something else?”

The unknown vs. the known
Menopause- “I feel and I have felt for about two years that I’ve been going through it, but I wasn’t quite sure, because I had a Mirena coil.”

“I think a lot with these sites- […]I think a lot of the sites at the top are sponsored aren’t they. So they’re clinics and they’re- and so you go to the first one and they’re always, “this could happen so you need to-“. Whereas if you onto NHS choices straight away, and this is where I know I’m sensible and this is what I *should* do […] erm then you start thinking all manner of stuff; that that’s it. I’m going to die of cancer, I’m going to die and I’m going to be gone within 12 months and you know it’s probably been there for months and it’s only now starting to have symptoms.”

The paradox of knowing
“But this time it came on and because it was so bad and obviously coming in here and they’re saying, “Oh we have to do this, that and the other” and whatever, it got me a bit more worried about it that I think the first time, but as it’s- you know when they said the lining has gone from 3 millimetres to 20 from the last scan that I had, sounded serious.”

“I’d rather have it checked and be told there’s nothing than be sitting and wondering and worrying unnecessarily, and just go get it sorted out and then it’s finished and you know what it is. Even if it’s not very nice you know what it is and you can deal with it whatever way.”

Searching for a cause
“I assumed it was that the coil had basically come to the end of it’s shelf like, because it was in 3 or 4 years longer than it should have been”

Still up in the air/ Book remains open
“all I want to know is, are there tests that you can say that, yea, “Yea, you’re in the middle. You’re coming towards the end.” But I don’t even know if that exists so. So, but he didn’t say it didn’t exist, other than, that all we know is when you’ve completely finished. […] I think for me I would rather have that kind of information. Erm, but I obviously didn’t get it.”

The conflict with severity
…
Weight and the uncertain risk
…

<u>The chaotic body:</u>

Shared vs. unique experience
Luckily I was like, ‘’Oh you’re so bloody stupid. How may other women do you think have had it? They were fine. You’ll be fine.” So, yea.

“But having come from a family with lots of different types of cancer, erm, cervical, breast, stomach, bowel… you just, you’re drawn to it I think Because you think, ‘well everyone else has had it, so therefore I must’. “

Exposing the chaotic body (e.g. weight gain, hot flushes, bleeding)
“But obviously at work and stuff I just feel like I’m- I get hot and that- I feel like that I’m a bit riffy, and people will think- I know I’m not, because I’m like really clean and stuff, but I think it’s just like gets into your head a bit and then once you start worrying about stuff, or me anyway.”

“It’s a bit (sigh) frightening, because of the amount and the size of the clots, and having an office based sit down job, I was- because the two times it came on it came on suddenly without warning and it literally poured out of me and my jeans were wet and everything and I had to- both times, once I was at work, the last first one and this one I’d gone for counselling and I’d got out of the car and I thought ‘Oh’ being an age I thought (laugh) I must have weed myself, but obviously I realised it was blood so I had to go back home. But it’s- it is frightening. It’s embarrassing.”

“I was sitting in the back of my cousins car and I had towels all over the place, which again is embarrassing. And then when I got there they go cream settees. And I was like, “Oh GOD I don’t want to sit down!” So I stood up and like, so they must have thought I was a bit mad as to why I wouldn’t sit down. But I had to go to the toilet every 5 minutes just to make sure that- because I think you get, well I do anyway, get a bit obsessed. ‘Oh I can feel a bit, so I’d better go to the toilet otherwise it’s gonna leak through’. Ern, so it’s just it’s not very nice. It’s not very pleasant.”

“I feel and I’ve been saying to people at work, “Do I look red? Do I look red? Am I sweaty? Are my trousers alright? Can you see anything?” And I mean there was nothing. Cause I kept going to the loo to make sure there wasn’t. But I think it just stars to get into your head doesn’t it? “

The internal hatred and mistrust
“And I used to do- two years ago I was doing back-to-back spin classes, and I was 15 stone. I’d lost 3 stone and I was just going under 15 stone- 15.10 or something like that. But I was going 6 days a week. I was doing back-to-back spins. Even though I’m quite big I’ve always been quite fit. Erm, but the last 12 months with all the problems with the bleeding and- it’s just… I just feel crap. [Begins to tear up] Sorry.”

The catch-22 of weight-loss and health
“I don’t know if it’s a coincidence, but I’ve had quite a bad time the last twelve or eighteen months with my family. And, because I had lost quite a lot of weight and I do feel I’ve put a lot on quickly, and it’s all around the bottom, and it’s difficult to shift it. So that’s kind of, and I don’t know whether that’s the menopause […] I suppose I’m just clutching at anything to

see if it's that or just eating and drinking too much. I don't know […] If that's the reason for it, because I-I don't eat unhealthily as such. I probably drink a bit too much drink, beer and stuff, and probably the times I'm eating is wrong, but I don't eat takeaways, don't have fish and chips and stuff like that. It's like salad and vegetables and what have you. Erm, erm, but I had, as I say, lost lots of weight, but I was doing a lot of exercise and then like this started. Like, my sister was not well, so it's probably a combination of everything."

"I've started putting weight on even though I was going to the gym and trying to eat healthily I was putting more and more weight on, and because of the way I was feeling with the- no with my thyroid before."

The penny dropped

Relief as short lived

"It was horrible. Horrible, nasty."

The penny dropped (i.e. the decision to seek help)

"I don't think it's very pleasant. It's- there's lots of different reasons. The mess of it, the embarrassment of it and the fact that you can't control it. And even if you wear underwear that – with pads and stuff it still always manages to get around it somehow. So I had- for the 11 days I had to have two for three towels on me and they- two or three towels on top of me and a shower curtain on top of the bed, you know on top of the bottom sheet. Not because I didn't- I didn't bled through in the night, but I was frightened to and I think I was going a bit obsessed with it all."

"I think it make you, well it made me feel dirty, like there's something seriously the matter with me. And then Google it and everything. As soon as you Google it, cancer is the first thing so you start thinking, Oh shit"

Interactions with healthcare for investigation toward treatment are uncomfortable at best and frightening, painful and intrusive at worst.

The feminine approach

"So I went to the doctor and it- and it was- I don't know whether it was [that he was] a man, but he was like, "well if it is it is [hot flushes]. You know, not a lot can be done about it. You're just going to have to role with it sort of thing […]. He didn't really, he didn't really- I suppose he kind of dismissed it really. I didn't- I came out more fed up that when I went in."

Doctors' actions are greater than the words they speak

"But thankfully the- I don't' know whether they're healthcare assistants or nurses that are in there when the senior nurse is doing it, the way they're chit chatting around you it kind of distracts you from it anyway. So that's-that sort of engaging in a bit of conversation with them sort of takes away from what's going on down there."

The necessary intrusion

"Stressed out, because it's one of those examinations where you need to be relaxed really, because the more tense you are the worse it is for them to try and open up the speculum and do what they have got to do if I'm like, trying to shut everything down to stop them so. Erm, and-and even though I try and relax it’s-it’s just- it’s just not nice is it, that’s particular part of it”

“I’d rather do that than sit at home suffering and not do anything. Erm, because I don’t know I just don’t think it’s worth it. That’s what the hospitals and the doctors are there for isn’t’ it?”

STACY Case Summary: BMI: 39; Time to booking= 0 days; booking to attendance= 0 days; Total time to help-seeking= 0 days

Experience of the Menopause: Experience of hot flushes, “I can feel heat coming all up my body, my face goes very very red [and burning of the ears] and I’m just sweating really really bad”. It is socially embarrassing and interrupts on nights out, interrupting the dancing, there’s no escape “if I were at home I’d just fling everything off, but obviously you can’t when you’re out, but that’s how intense I get”. Advice from friends doesn’t help relieve her of hot flushes. She went on HRT to reduce bleeding during menopause and help with other symptoms of menopause which also included dry skin all over body, in private area, and pimples. Being period-free feels great, and no matter how much of a hindrance hot flushes are, the experience of menopause is better than her previous experience of regular heavy periods, “Felt really naff” about periods”. She has been told she’s in the peri-menopausal stage of menopause. Peri-menopausal means, “I suppose on the borderline of still having slight periods, but not still having your periods.”

Experience of PMB: Episodes of irregular spotting 3 times over a year. Each lasted 3 – 5 days. Experience of bleed is different than normal period, lighter, not painful and no tugging. There wasn’t a lot of blood, but enough to wear a pad. After history of difficult periods, Difficulty history with periods (long lasting, heavy, fatigued, and interrupted daily life)**. “**Oh God, it’s all going to start again now. Bleeding again after being period-free for 5 or 6 months and feeling that she was through the menopause and therefore done with bleeding, left her feeling deflated and disappointed.

Making sense of PMB: “This isn’t normal, why I’m bleeding again?” Things become concerning when they are not normal/ordinary, because it is unknown. “I always think the worst.” The worst thing that the bleeding could mean is cancer and thought bleeding was connected to abnormal smear results (cervical problem). Hypo-thyroidism discovered during time of bleeding denotes a connection between the two conditions. She made herself ill with worry = mental health illness of depression and panic attacks, thinking that it could be cancer.

Reason for seeking help: “This isn’t right. It needs acting on straight away in case it could be cancer.”

Reason(s) for delay: …

Position: Initial voice is very manner of fact as though reporting incidents to a doctor. Awareness of the position of the researcher as different and unknowing of her experience of obesity, therefore she often takes the *expert position* to teach the researcher about the experience of those like her.
Supportive role of family member is to be level headed and attend appointments with her.
It’s the *patient’s responsibility* to insist to be seen by a healthcare professional
Her stance moves from an expert stance to a personal one through the course of the interview.

Process: Phoned the GP straight away on second episode of bleeding and because had been to PMB for first bleed was fast tracked to the PMB clinic (within one week).

Experience of help-seeking: Used to feel embarrassed undressing in front of doctor, but it's the furthest thing from her mind now. The mind-set that she's not unlike other patients (she's not the only one) "you need to sort this problem out. They see different sizes every day. They're not going to take any notice" During visit, fear interferes with comprehension of information communicated by consultant during visit, because she is fearing the worst. So it has been very difficult" "just had it in my head that it's not going to be good news and I don't' know why. I think it's because of the, how many times I've got the re-occurring bleeds, and they seem to have been getting worse each time. Yea." Daughter is positive support system against illness worry; with her during visit and does the listening for her. Received conflicting information from gynae consultants as to whether or not to investigate bleeding that creates a distrust about their knowledge in what's best for the patient, "I was just unsure that they knew what they were talking about." Do doctors really know best?

Experience after help-seeking: The bleeding continued, and worstened to heavy long lasting bleeds, losing clots. Even though she's been looking forward to her holiday the results of the biopsy has been weighing on her mind. "the last few times I've had to come up here, I've just had a really negative effect on everything going on… I can't wait till it's all over and done with." She's been told the bleeding will stop once the polyp has been removed and she *can't wait.*

Previous help-seeking experiences: Didn't attend screenings until she was in her 40s, because was frightened and embarrassed to show body to a male doctor. However is now familiar with the service due to attendance at regular screenings for abnormal smears.

Reasons for seeking help: Things that are not normality need to be addressed by medical help: "You know so it was a big change for me and that's why I new I needed to get on top of it and get it sorted out." The knowledge that smears can save your life over-rides the embarrassment of the examination and showing body to a male doctor - if they don't look they can't help. Jade Goody celebrity gnae cancer death: "I think it brought to light that if you didn't go in for your smears, cancer could quickly spread, and I think that did frighten a lot of people and prompted them into having smears."

Knowledge of Gynae cancer/menopause: She has an awareness of the consequences of not attending screenings and that womb thickening is a bad thing. Is confused about the stages of menopause and what each stage means, nevertheless she understands that menopause is a long lasting condition that can sometimes last up to 5-10 years.

Researcher Reflection: Information regarding menopausal stages, what they mean and how long they'll last is not explained to patients by doctors? Conflicting medical advice, put the decision on the patient and that is what made her not follow up on the first PMB investigation, because the decision for investigation should be made my the doctor and not the patient?

Body Image: "I hate my body": Significant weight gain over the past 4 years that's been a struggle to keep off. Feels at a standstill. It's difficult finding nice clothes that fit which is important, because she wants to fit in with friends who where their nice clothes better than she does due to slimmer figures. I would never wear shorts. Weight gain was caused by a combination of stopping smoking, underactive thyroid, and asthmas steroid treatment (weight is a side effect of steroid treatment), and being alone and depressed which encourages bad eating habits. Losing weight is a catch-22 that is frustrating, because the methods of losing weight can flair up her comorbid asthma, which is treated by using weight-gaining steroids. GP gave Slimming World vouchers, but they didn't help, need more help losing weight to teach appropriate exercise rather than just controlling what she eats. Weight impact: "I've found the weight gain very very hard to live with to be honest". Feels *disgusted* that she's let herself get like this when she sees her naked body in the mirror. There is self-blame at times for allowing the weight gain, but obesity what also not caused only by her doing, but by her health problems (catch-22 of treating co-morbidities).

Evidence for themes:

<u>The ambiguous enmeshment of PMB and menopause:</u>

The shock of a bleed (after months without)
"You're just not prepared for it. Obviously because I hadn't had bleeds for months and months I didn't keep any sanitary wear in the house, you know, so it was a big shock having to go out and start buying things again."

"I did find it very very stressful and to be honest when I did have the bleed I was really disappointed, because I thought I'd finished with periods. I didn't honestly realise that you could be in the menopause up to 10 years."

"I didn't have any pain neither. I've always had painful periods, but with this I didn't. I didn't have any period pains or the tugging, so again I felt that that was something different for me."

No-one has the answers
"Yea, and I've tried different things, because all of my friends are 10 and 15 years older than me. We all met as part of a bereavement group and I've had different advice. One's told me to try ginger, cod liver oil, and I've tried everything, and for me nothing works for me at all [to relieve hot flushes]"

"Yea I saw two different consultants here, because I used to come here an awful lot, but I think that was because of my irregular smears and everything like that." […]I was just unsure that they knew what they were talking about."

The unknown vs. the known
"This isn't normal, why I'm bleeding again?" Things become concerning when they are not normal/ordinary, because it is unknown. "I always think the worst."

"Erm, and for me I'm a worrier so it's made me quite ill, but it's just because of the way I am."

The paradox of knowing

"just had it in my head that it's not going to be good news and I don't' know why. I think it's because of the, how many times I've got the re-occurring bleeds, and they seem to have been getting worse each time. Yea."

"She [the doctor] was trying to sort of make me see sense in saying sort of, "Look don't worry yet until you've had all the tests and everything like that." You know, but for me it's a big thing, and I don't really- and I do fear the worst all the time. So it has been very difficult for me. Very stressful."

Searching for a cause

"Cancer. That's what I thought straight away, without listening to anything they were saying. Everything just went over my head."

Still up in the air/ Book remains open

"I haven't been able to go out because the bleeding's been so bad. I had to be rushed to hospital a fortnight ago on the evening, because I was losing that much blood and really huge clots. Erm and that's when they gave me tablets to control the bleed"

"Yea so it's been very very hard. I can't wait till it's all over and done with. Yea. I'm hoping that when the polyp has been removed, that's it then. I've been told it will be, so I can't wait."

The conflict with severity

"I'd got up out of bed. I hadn't actually felt anything, but there was blood on my pyjamas"

Weight and the uncertain risk

"I've put an awful lot of weight on, but they've also discovered I've got an under-active thyroid as well round about the same time that my periods where becoming irregular so I think that's contributed as well to be honest."

The chaotic body:

Shared vs. unique experience

"I used to feel so embarrassed of if I'd have to see the doctor and knowing that I'd have to strip off. Now I don't. It's the furthest thing from my mind. Now I just go with, 'you need to sort this problem out. They see different sizes every day. They're not going to take any notice'."

"I know, one of my friends who's 62, she still has the flushes now and she's been period free for over 10 years, but she is still getting the flushes. So I'm not sure. I don't know."

Exposing the chaotic body (e.g. weight gain, hot flushes, bleeding)

"I can feel heat coming all up my body, my face goes very very red [and burning of the ears] and I'm just sweating really really bad". It is socially embarrassing and interrupts on nights out, interrupting the dancing, there's no escape "if I were at home I'd just fling everything off, but obviously you can't when you're out, but that's how intense I get".

“Always constantly having to put cream on, because I just feel so tight and itchy [vaginal skin], yea. But the GP said to me, “If you take the HRT it would rule everything like this out”. But I just didn’t want to take it, because she said it will give you your periods back.”

Hot flushes: “I find them very annoying to be honest. I can just be sitting normally out with friends and then all of a sudden I can feel heat coming all up my body, my face goes very very red and I’m just sweating really really bad to- I carry now with me, it’s like a water mist and I always spray my face and I’m constantly fanning myself while I’m out, and also clothes, it’s changed the way I wear my clothes when I’m out on an evening. I only wear very very light clothing, because otherwise I’ll just sweat terrible.”

The internal hatred and mistrust

“I just hate the roundness of my body. I used to be quite… Nowhere near as slim as you, but I used to have quite a nice figure where I was happy with, but now I have so many different rolls of fat. You know, and I struggle to find clothes, nice clothes anyway.”

“I still like wearing my cropped trousers, but I don’t feel as if I can dress as lightly. I would never wear shorts. I wear shorts in my back garden. I would *never* wear them on holiday, because I just feel that my body is so horrible at the minute.”

“Yea, it’s really frustrating for me and I do view my body differently than how I did like 5 years ago. I was so much more happy with my shape and everything like that and I mean now I know I’ve got to lose 5 and a half stone to be what I should be for my height.”

“Because I’ve battled with depression as well, yea and I think for me being at one alone- especially when I sitting watching telly at night it’s the easiest thing to pick up a packet of crisps, you know, while you’re watching the telly.”

The catch-22 of weight-loss and health

“I’m very aware that with my weight and my shape I can do so much to change it, but then if I start exercising I might make myself ill with my asthma, then I have to go onto steroids. Steroids naturally make me gain weight. So for me it’s been like a catch-22. So I’ve found it very very frustrating.”

“Well some days I can get up and get in the shower and as I’m getting dressed I can look at myself and feel real disgusted that I’ve let myself get like this. But to a certain extent it is my own doing, but a lot of it is health problems as well. So, and I’ve found that as I’ve got older it’s definitely a lot harder to lose the weight. It really is.”

“So I have to strive to lose the weight as best as I can really. I find it hard to use gyms, because my asthma. Erm, I do a lot of walking which can level me out and I can lose a few pounds, but I have bad eating habits as well, which doesn’t help […]”

The penny dropped

Relief as short lived
"So then I went from about March, April to nothing at all to the November so it was roughly about 5, 6 months and then it just started up again."

The penny dropped (i.e. the decision to seek help)
"This isn't right. It needs acting on straight away in case it could be cancer."

Interactions with healthcare for investigation toward treatment are uncomfortable at best and frightening, painful and intrusive at worst.

The feminine approach
"I find them quite painful, erm and at my GPs you could never guarantee to see a lady, and I just found it so embarrassing seeing a man doctor."

"Even though now I know that it's something that can save your life and so I don't care if someone looks at me now."

Doctors' actions are greater than the words they speak
"Worrying for me, but with me even though they'll talk to me and tell me what things are it doesn't stay in there. Whereas when I bring my daughter with me she takes in everything they're saying and then she can say to me later, "This is what it is". But for me it's just a fear thing and I think that's why I don't keep it stored. So you know I think it was a real worry to me."

"Cancer. That's what I thought straight away, without listening to anything they were saying. Everything just went over my head."

The necessary intrusion
"I think it [Jade Goody celebrity death] brought to light that if you didn't go in for your smears, cancer could quickly spread, and I think that did frighten a lot of people and prompted them into having smears. I know for myself I decided that if I wanted to stay healthy it's something I had got to have checked. You know, and that's why I just started to have my smears then on a regular basis."

"Yea, and I'm not embarrassed by a doctor looking at my body anymore, because I know that if they don't look they can't help. Even though I feel really strongly about my body, I know that if it's something they need to do then they just need to do it."