**A thesis submitted in partial fulfilment of the regulations for the degree of**

**Clinical Psychology Doctorate at the University of Birmingham.**

# VOLUME I

## RESEARCH COMPONENT

## Literature Review and Research Paper

**by**

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# OVERVIEW

This thesis is submitted in partial fulfilment of the requirements for the degree of Clinical Psychology Doctorate at the University of Birmingham. There are two volumes to the thesis, which illustrate research (Volume I) and clinical work (Volume II).

**Volume I** of the thesis contains a literature review, research paper, and public domain paper. The literature review summarises research that explored the impact of intimate partner or social support on antiretroviral medication adherence for people living with HIV (PLWH). The research paper describes a qualitative study exploring women and their intimate partners' experiences of body image and sexuality after undergoing a mastectomy and reconstruction for breast cancer. It is intended that the research report will be submitted to 'Psycho-Oncology' for publication and the literature review will be submitted to 'AIDS and behavior'. The public domain paper summarises both the literature review and research paper.

**Volume II** of the thesis contains four clinical practice reports (CPRs) and the abstract of a fifth which was presented orally. Each report was completed over the duration of the course and reflects some of the work carried out on clinical placements. These reports include; CPR1 is the case of a 6-year old boy presenting with encopresis formulated from a behavioural and psychodynamic perspective. CPR2 is a case study of 12-year old boy presenting with separation anxiety. CPR3 documents a single-case experimental design that assessed the effectiveness of a Cognitive Behavioural Therapy intervention with a 75-year old woman with panic attacks. CPR4 is a small-scale service evaluation assessing psychological need and barriers to service engagement for people living with HIV. An abstract outlining

CPR5, a clinical presentation about an assessment for a 12-year old boy attending a community learning disability team who was displaying anxiety and anger, is also included.

# DEDICATION

To Grandma, Darren, Baby Pearl, Michael, Marie and Uncle Paul

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# WHAT DO WE KNOW ABOUT THE IMPACT OF INTIMATE PARTNER OR SOCIAL SUPPORT ON MEDICATION ADHERENCE? A SYSTEMATIC REVIEW

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# ABSTRACT

Research suggests that effective intimate partner or wider social support can lead to better adherence to antiretroviral treatment (ART) and improved health outcomes for people living with HIV. This review aimed to describe and synthesise the research conducted from 1996 to the present day to answer three research questions relating to intimate partners, wider social support and psychological interventions involving these types of support in increasing ART adherence. Twenty-two papers met the inclusion and exclusion criteria for inclusion in the review. Eight reported on studies focused on intimate partners, a further eight studies discussed wider social support for example friends, families or ‘medicine companions’ and six studies tested the efficacy of an intervention based on intimate partner or social support to increase the medication adherence of people living with HIV. The review found that there are limited studies demonstrating strong relationships between social support and adherence and even less that systematically test the utility of providing social support interventions. Therefore research on increasing the types of intimate partner or social support that have shown promise in increasing adherence is needed to further develop this evidence base.

**Keywords:** HIV, medication adherence, anti-retroviral medication, social support, intimate partners, adherence support, treatment partners.

# INTRODUCTION

There are an estimated 86,500 people infected with human immunodeficiency virus (HIV) in the UK (Health Protection Agency, 2010a), with 26% of these unaware of their HIV positive status. The prevalence of HIV in the UK is higher among men who have sex with men and black African heterosexuals. HIV has a direct effect on the immune system infecting a sub-group of lymphocytes called CD4 T Cells. HIV leads to a progressive reduction in the effectiveness of the immune system by reducing the number of these CD4 cells. Compromised CD4 cells can lead to an individual experiencing opportunistic tumours, viruses and infections that can ultimately lead to premature death if not treated appropriately. However, HIV is now recognised as a long-term health condition due to advances in medical care and the introduction of Highly Active Antiretroviral medicines (HAART) in the mid-1990’s (Delaney, 2006). People living with HIV (PLWH) can now expect to live longer, with the previous image of HIV as a terminal illness slowly changing to that of a chronic condition. Therefore HIV care is now focused on disease management and quality of life rather than in previous years where deterioration and palliative care were key drivers in providing medical and psychological care.

Disease management in HIV primarily takes the form of complex medication regimes and regular medical monitoring. These often complicated medication regimes aim to inhibit replication of the HIV virus and thus suppress the virus to undetectable levels in the body, known as ‘HIV suppression’. This suppression can lead to declines in HIV-associated morbidity and mortality. However, for sustained suppression of HIV in the body, and to prevent viral resistance to the medication that would render the medication ineffective, the antiretroviral therapy (ART) must be adhered to at least 95% of the time (Murphy, Lu, Martin, Hoffman, & Marelichl, 2002). Adherence broadly relates to the “extent to which a patient’s health-related behaviours correspond with medical advice” (Eldred, 1997). Within ART this translates to taking the right amount of medication, at the right time and with the correct dietary conditions. Despite this, PLWH often fail to maintain optimum adherence rate with average adherence of 60–70% being reported (Simoni, Frick, & Huang 2006).

Medication non-adherence is complex and can be influenced by factors related to: patient characteristics; contextual or environmental factors; aspects of the provider and the patient-provider relationship; and variables related to the treatment regimen or illness (Ickovics & Meisler, 1997). Specifically for PLWH non-adherence has been consistently associated with reported symptoms and adverse ART drug side-effects, psychological distress, lack of family or social support, complexity of the ART regimen, low patient self-efficacy, and inconvenience of treatment (Ammassari et al., 2002).

Contextual and environmental factors relating to marital and family functioning can impact strongly on medication adherence, for example DiMatteo (2004) reported adherence to medical regimes that were 1.74 times higher in patients from cohesive families and 1.53 times lower in patients from families in conflict. Family and couple-based interventions have demonstrated effectiveness in improving overall health outcomes in diseases such as chronic mental illness (Rea et al., 2003), substance misuse (Velleman, Templeton & Copello, 2005), diabetes mellitus (Pendley et al., 2002) and cancer (Weber et al., 2004). Similarly associations between adherence and practical, emotional, and social support, family cohesiveness and conflict, and marital status have been demonstrated (DiMatteo, 2004). A recent meta-analysis of cross disease studies investigated the characteristics and findings of couple-oriented interventions for chronic physical illness (Martire, Schulz, Helgeson, Small & Saghafi, 2010). The authors found that couple interventions had significant effects on improving patient depressive symptoms, marital functioning, and pain and were more efficacious than both patient psychosocial interventions and standard care.

A number of interventions to increase adherence have been reported in the literature, for example cognitive behavioural interventions (Wagner et al., 2006; Safren et al., 2012), behavioural approaches such as Modified Directly Observed Therapy (mDOT), contingency management (Rueda et al., 2006; Haug & Sorensen, 2006) and patient education programmes (Goggin, Liston & Mitty, 2007). However, Interventions to promote or increase adherence are reliant on accurate and adequate adherence measurement.

Two commonly used approaches to defining an individual's adherence to medication are to consider whether any pills are missed over a specific time period or whether the patient has exceeded a specified percentage of doses taken. This approach may also include whether the medication is taken at prescribed times and as directed (Fogarty et al., 2002). Adherence can be assessed as a continuous variable, for example the proportion of prescribed doses taken as measured by self-report, or medication available for consumption by pharmacy refill records; this is often measured in the 3 days prior to assessment. The validity of self-report in medication adherence has obvious drawbacks with over-reporting of adherence possibly taking place. An alternative method of recording adherence to dose and timing is the use of an event monitoring system attached to the medication bottle

(MEMS cap). This system uses microprocessor technology to record the exact date and time that a medication bottle is opened, and therefore, when medication is assumed to have been taken. This data is collected electronically to provide an alternative to self-report adherence data.

Intimate partner or social support for PLWH can be categorised in differing forms. House and Khan (1985) described ‘appraisal support’, in the form of such as encouragement, feedback, affirmation and modelling from supportive others; ‘emotional support’, consisting of listening, caring and empathy; ‘informational support’, including information about HIV, medications and strategies to increase adherence. These forms of support are further contextualised by the dimensions (perceived or received support), sources (partner, family, friends, and professional supporters) and contexts (in a crisis, chronic stressful situation, everyday life). Interestingly, the literature indicates that perceived support has a positive association with wellbeing variables. Conversely, received social support is either unrelated or negatively related to increased wellbeing (Kaul & Lakey, 2003; Reinhardt, Boerner, & Horowitz, 2006). While some researchers have reached this conclusion following examination of both perceived and received support (Kaul & Lakey, 2003), the conceptual discussion about perceived versus received support has been informed largely by comparing findings of studies that included either received or perceived support.

In the last decade there has been a sharp increase in the number of studies attempting to assess adherence factors for PLWH. The importance of maintaining optimum adherence rates has resulted in clinicians and researchers seeking viable and efficacious strategies for enhancing medication adherence. Whilst support from partners, friends and family has been recognised as a factor in a complex picture of medication adherence, there are no studies that attempt to draw together this research with regard to PLWH.

# AIMS OF THE REVIEW

The aim of this review is to describe and synthesise the evidence in relation to the impact of social support and social support interventions on HIV medication adherence. In order to fully meet this aim, the review sought to answer the following questions:

1) How do intimate partners support medication adherence and what are the effects of this support on adherence?
2) Who else supports people on HIV medication and how do these supportive practices impact on medication adherence?
3) Are interventions aimed at intimate partner support or wider social support efficacious in increasing adherence to HIV medication?

# METHOD

## Search Strategy

The following databases were searched for the period 1996 - October Week 1 2011: EMBASE, MEDLINE and Web of Science and PsychINFO for the period 1987- October Week 1 2011. The date was chosen to reflect the introduction of Highly Active Anti-Retroviral Therapy (HAART) in 1996 (Kelleher, Carr, Zaunders &Cooper, 1996). The search terms used were: ("adherence" OR "medication compliance") AND ("partner" OR "couple" OR "intimate partner" OR "spouse” OR "significant others" OR "social support" OR "spouse” OR "treatment supporter") AND ("HIV" OR "human immunodeficiency virus") AND ("antiretroviral" OR "HAART"). The searches yielded 741 references, duplicates were then removed leaving 414 references. The remaining references were examined to identify those relevant to the topic under review. The articles were sorted by hand, each abstract was read and the reference lists reviewed for further relevant studies using the inclusion and exclusion criteria below. Appendix 3 contains a summary of this search process.

## Inclusion and Exclusion Criteria

Studies were selected for inclusion in the review if they directly assessed both medication adherence and intimate partner or social support. Qualitative and quantitative studies were included. Studies that referred to people under the age of 18, not in the English language, not subject to a peer-review process, were conference abstracts, not original research or books were all excluded. Papers that either studied the prevention of HIV, the assessment of sexual risk factors, assessed general support or only physiological outcomes were also excluded.

## Details of Papers Left for Review

Twenty-one papers were retrieved from the database search. The reference lists resulted in one further paper being included in the review. In total 22 papers were found to meet the inclusion criteria for review. Table 1 contains a brief summary of each paper in relation to country, aims, research design and sample size. Full text articles were gained through the University of Birmingham electronic journal access, by contacting the authors directly or through the interlibrary loans service. Appendix 4 contains summary tables for each paper in the review organised by research question.

## Quality checking process

Due to the small number of studies available that meet the aims of this study, all papers were included in the review. Efforts were made to differentiate between more or less rigorous studies in the synthesis of the data by utilising a quality checklist. A critical appraisal tool (Caldwell, Henshaw & Taylor, 2005) was selected as it fitted the aims of the review and enabled critical appraisal of both qualitative and quantitative designs. The questions were elaborated through peer discussion to more usefully address the specific aims of the critical analysis using further appraisal tools (Critical Appraisal Skills programme [CASP] 2006; Sale & Brazil, 2004). Appendix 5 contains a full example of an article subject to this quality checking process.

An overall numerical rating score was not chosen as a method to review each article, as the weighting of the features within the checklist may have resulted in skewed results and thus readers' interpretation of overall scores. To develop a scoring method for the studies reviewed an appraisal system adapted from Fowkes and Fulton (1991) was used. This method involved critiquing each criterion using either ‘++’ indicating good, no problems identified, ‘+-’ indicating minor problems identified, and ‘- -‘ indicating major problems identified. Appendix 6 contains the quality scoring for each paper in the review organised by research question.

**Table 1: Summary table of studies included in the current review**

| Author(s) & Year | Country | Aims | Method | Design | Participants |
|---|---|---|---|---|---|
| Do et al. (2010). | Africa | To identify psychosocial factors that affect medication adherence | Quant | Cross-sectional survey | n=87 |
| Feaster et al. (2010). | US | Test efficacy of SET (a systemic therapy) against 2 control conditions | Quant | RCT | n=156 |
| Foster et al. (2010). | Africa | Report on the baseline characteristics of 'medicine companions' (family members including children or partners) - how chosen, what role played and how useful. | Mixed | Interviews and questionnaires | n=1453 and 40 in-depth interviews. |
| Gardenier, Andrews, Thomas, Bookhardt-Murray & Fitzpatrick (2010). | US | To describe perceived social support in comorbid PLWH in a day care programme and explore diffs between adherent and not adherent patients | Quant | Cross-sectional survey | n=56 |
| Knowlton et al. (2011) | US | Investigate types of social support and impact on adherence | Quant | Cross-sectional survey | n=462 |
| Knowlton et al. (2011). | US | Examine associations of partners and other social factors with ART adherence among women | Quant | Cross-sectional survey | n=154; |
| Koenig et al. (2008). | US | Does a social support intervention improve adherence compared to standard care adherence counselling | Quant | RCT | n=226; |
| Lopez, Jones,Villar-Loubet, Arheart, & Weiss (2010). | US | To investigate the extent to which IPV influences medication adherence and to determine whether there were any differences in adherence rates between genders | Quant | Cross-sectional survey | n=190 |
| Marino, Simoni, & Silverstein, (2007) | US | What is the experience of providing peer support in ART | Qual | Grounded theory – 1-1 interviews | n=9 |
| Murphy, Lu, Martin, Hoffman & Marelich (2002) | US | Does a multicomponent multidisciplinary intervention increase adherence to ART compared to treatment as usual | Quant | RCT | n=33. |
| Nachega et al. (2006) | Africa | Aimed to investigate patient and health care provider perceptions about support strategies that would encourage the highest rates of ART adherence | Qual | Content analysis – 1-1 interviews | Focus gp x 2 n=12<br>- interviews HCP n=7 |

| Author(s) & Year | Country | Aims | Method | Design | Participants |
|---|---|---|---|---|---|
| Power et al. (2003) | US | Examined relationships between Adherence and social support (3 types) and use of 2 coping skills (denial and SU) | Quant | Cross-sectional survey | n=73 |
| Remien et al. (2005) | US | Evaluation of a couple based intervention focused on improving communication, enhancing problem solving skills, psychoeducation on adherence (led to improvements in adherence) | Quant | RCT | n=215. |
| Simoni, Frick, Lockhart & Liebovitz (2002). | US | To determine rates and correlates of adherence | Quant | Cross-sectional survey | n= 50 |
| Simoni, Frick & Huang (2006). | US | Test proposed model of adherence. | Quant | Cross-sectional survey | n=136 |
| Simoni, Pantalone, Plummer & Huang (2007) | US | To evaluate a peer support intervention grounded in social support model of adherence that posits a central role for depressive symptomatology in non-adherence. | Quant | RCT | n=136 |
| Skovdal, Campbell, Nyamukapa & Gregson (2011) | Africa | To qualitatively explore how male denial of HIV (through concept of hegemonic masculinity) impacts on female partners ability to access and adhere to ART | Qual | Thematic interviews& focus groups | n= 53 patients<br>n=25 healthcare |
| Stubbs, Micek, Pfeiffer, Montoya & Gloyd (2009) | Africa | Evaluate the association between type of tx partner (community based - trained community activists - and self-selected - family members or friends) and adherence to ART in first 6 months of treatment | Quant | Analysis of case records | n=375 |
| Taiwo et al. (2010) | Africa | Assess the efficacy of patient-selected treatment partners on adherence outcomes of ART. | Quant | RCT | n=499 |
| Wagner, Remien, Carballo-Dieguez & Dolezal (2002) | US | Assess medication adherence and its correlates in HIV-positive members of HIV mixed status couples. | Quant | Cross-sectional survey | n=40 couples |
| Wrubel, Stumbo & Johnson (2008). | US | Describe the specific practices offered within gay male couples to support their partners with HIV in maintaining adherence to their medication regimen. | Qual | Team based analysis | n=20 couples |
| Wrubel, Stumbo & Johnson (2010) | US | To understand the nature of desired support, what is actually offered, and what is accepted, as well as how and when they benefit adherence. | Qual | Team based analysis | n=20 couples |

# METHODOLOGICAL OVERVIEW

The methodological issues found during the critical appraisal process are considered here in relation to all the papers included in the review. Following this overview, the findings for each of the three research questions will be synthesised in the subsequent chapter.

The majority of studies included in this review employed quantitative designs (n=16) of which six utilised a randomised controlled design (RCT) to test the efficacy of a supportive intervention to increase adherence (Remien et al., 2005; Feaster et al., 2010; Murphy et al., 2002;  Simoni, et al., 2007; Koenig et al., 2008; Taiwo et al., 2010). Nine of the remaining quantitative studies employed a cross-sectional survey design (Do et al., 2010 Gardenier et al., 2010; Knowlton et al., 2011: Knowlton et al., 2011; Lopez et al., 2010; Power et al., 2003; Simoni et al., 2006; Simoni et al., 2002; Wagner et al., 2002). One study analysed data from clinical case records (Stubbs et al., 2009). Five studies utilised qualitative designs and one study used mixed-methods (Foster et al., 2010). These studies differed considerably in their scope and aims.

Eight studies investigated the impact of intimate partners on medication adherence (Do et al., 2010; Knowlton et al., 2011a; Knowlton et al., 2011b; Lopez et al., 2010; Skovdal et al., 2011; Wagner et al., 2002; Wrubel et al., 2008; Wrubel et al., 2010) and a further eight studies investigated wider social support outside of the intimate partner relationship (Foster et al., 2010; Gardenier et al., 2010; Marino et al., 2007; Nachega et al., 2006; Power et al., 2003; Simoni et al., 2002; Simoni et al., 2006; Stubbs et al., 2009).

The recruitment of participants in the studies was varied; however no study used a truly random sample, although the RCT’s did employ some method of randomisation to conditions. The majority of participants were recruited from clinic samples or from clinic waiting rooms (e.g. Simoni et al., 2006; Simoni et al., 2002; Simoni, et al., 2007). Other recruitment strategies involved putting adverts in local HIV related publications or within hospitals (e.g. Feaster et al., 2010; Murphy et al., 2002; Power et al., 2003), this strategy would ultimately have resulted in sampling bias and therefore not a truly random sample.

There is no accepted gold standard for adherence assessment; the papers reviewed here used different assessment methods across studies, including patient self-report over 3 days (Murphy et al., 2002;  Simoni et al., 2002; Simoni et al., 2006; Wagner et al., 2002), 4 days (Do et al., 2010; Feaster et al., 2010; Gardenier et al., 2010; Lopez et al., 2010; Power et al., 2003), 7 days (Knowlton et al., 2011a; Knowlton et al., 2011b),  and 30 days (Wrubel et al., 2008). Other assessments utilised monitoring devices over a period of between 3 days and 6 months (e.g. MEMS, Remien et al., 2005; Koenig et al., 2008; Simoni et al., 2007), review of pharmacy records (Stubbs et al., 2009; Taiwo et al., 2010). Five studies did not formally report adherence (Foster et al., 2010; Marino et al., 2007; Nachega et al., 2006; Skovdal et al., 2011; Wrubel et al., 2008).  It has been suggested that adherence may be underestimated by MEMS and overestimated by patient self-report (Liu et al., 2001). Therefore, without the use of standardised measures of adherence across studies it is not possible to accurately assess the claims made as to the effects of partner or social support on medication adherence. However, a meta-analysis has already highlighted the validity of self-reports when measuring adherence (Nieuwkerk & Oort, 2005), therefore this is thought to be a reliable measure providing it is measured consistently.

Non-adherence is defined in this study in different ways by using various cut-off points for percentage of doses taken or by creating summary indexes based on multiple questions or multiple measures to categorise patients as adherent or not. Therefore a person who is adherent in one study may not be categorised as adherent when assessed by another set of study measures. Also, the possibility of drug-specific adherence rates needs to be considered when overall adherence is assessed, as there can be differences due to acceptability of different ART regimes, such as pill burden or medication side effects. The articles reviewed here did not take into account longitudinal adherence patterns; adherence was commonly measured for 3 or 4 days prior to reporting. Adherence is a dynamic process; thus adherence behaviour can change over time, perhaps due to ART initiation, regime change or personal circumstances. Consequently, when to measure adherence is a key unanswered question.

Further limitations around the assessment of correlates of ART adherence are evident. In the studies reviewed here different measures have been used to investigate factors hypothesised to be related to medication adherence (e.g. Doh et al., 2010; Simoni et al., 2006). In some studies a measure has been designed for that study, with limited testing of the reliability and validity for the study population or variables being measured (e.g. Knowlton et al, 2011a)

Characteristics of the sample in each study represent a limitation in these papers. Sample sizes were small in many quantitative studies; for example 11 studies had a sample of less than 200 participants. Some studies were underpowered (e.g. Simoni et al., 2007) potentially resulting in a Type 2 error and making it more difficult to detect the small intervention effects in these studies, including the additional power needed to detect differences between two trial interventions to be confident in the validity of findings from randomised controlled trials. Other studies did not report that they had conducted power calculations, therefore it was not possible to know if the sample size was adequate (e.g. Gardenier et al., 2010; Power et al., 2003; Simoni et al., 2002; Simoni et al., 2006).

Only two studies that used standard measures failed to discuss the reliability and validity of the measures (Koenig at al., 2008; Power et al., 2003). The majority reported the internal consistency of their measures by reporting the coefficient alpha (Cronbach, 1951). A range of measures were used to assess psychological variables, supportive relationships and other outcomes; however due to the limited space within this review, a full overview of the strengths and limitations of each of these measures cannot be discussed. Further details of specific measures used in the studies can found in Appendix 4. The majority of quantitative articles reviewed used appropriate statistical tests and controlled extraneous variables within the analytic process. Only one study failed to report the statistical results of their analysis or provide tables to allow the reader to review the stated results (Do et al., 2010).

Participants who dropped out of an RCT were generally subject to intention-to-treat analysis. Participants are analysed in the groups to which they were randomised, even when they drop-out of their experimental group. This form of analysis helps prevent bias caused by the loss of participants, and the resulting imbalance between comparison groups; however it has benefits and disadvantages. Missing data would be an issue as assumptions about the relationship between dropout and the study results would be made by the researchers in order to present results which account for the missing data.

Within qualitative studies very rarely did they state the philosophical background to their study or considered the epistemological or reflective positions or any potential biases. This led to these studies receiving poorer quality ratings than the one study that did draw heavily on a theoretical background (Skovdal et al., 2011). Further details of the characteristics of each study and a synthesis of findings can be found in the following chapter.

# SYNTHESIS

## Question 1 - How might the presence or absence of intimate partner support be associated with mediation adherence?

A total of eight papers directly assessed factors relating to intimate partners and medication adherence. Five of these studies utilised non-experimental survey designs to investigate associations or relationships between intimate partners and medication adherence (Knowlton et al., 2011a; Knowlton et al., 2011b; Lopez et al., 2010; Wagner et al., 2002; Do et al., 2010) and three papers used qualitative methodologies to explore the support practices of men in heterosexual couples in Africa and men in same sex couples in the United States (Skovdal et al., 2011; Wrubel et al., 2008; Wrubel et al., 2010).

Three studies found that intimate partners have a negative impact on medication adherence. In a study to identify the psychosocial factors affecting medication adherence in a sample of men and women in Botswana (n=300), Do et al. (2010) found that alcohol use, depression, and nondisclosure of positive HIV status to their partner were predictive of poor adherence. This non-disclosure of HIV status could result in a lack of HIV specific support in the home, particularly around medication adherence, and may result in further physical and emotional isolation. However, this study does not state the method of analysis or present the statistical findings; 72% of respondents did disclose their HIV status and 16% did not answer the survey question, therefore there were only 12% (n=36) of respondents who did not disclose their status.

A further study investigating factors affecting medication adherence sampled mixed HIV status (seroconcordant or serodiscordant) heterosexual couples (n=190) in Miami, Florida (Lopez et al., 2010). Lopez and colleagues found that intimate partner violence (IPV) resulted in lower adherence for females but not males. Male participants in this sample were more likely to use substances, which in turn resulted in reduced medication adherence. Knowlton et al. (2011b) similarly investigated the factors affecting medication adherence in a clinic population of adherent and non-adherent women (n=104) living in Baltimore, United States. Knowlton and colleagues found that adherence was highest among those who did not have a partner and lowest among those with an HIV positive partner. Moreover, HIV positive versus other serostatus main partners were most likely to provide medication-taking assistance and to be preferred in helping participants deal with HIV, yet were no more likely to be nominated as the most helpful to them. This study suggests that women in this sample have a perceived unmet need in relation to their support from their partners.

An additional study by Knowlton and colleagues (Knowlton et al., 2011a) assessed the function of support and its impact on adherence in a sample of men accessing an HIV service also in Baltimore. The main finding suggested that better adherence was associated with having informal care but was not necessarily associated with having an intimate partner or larger number of friends in their social network. Knowlton and colleagues also reported that men reciprocating support was critical to the effective functioning of their supportive relationships.

A final study, assessing the psychosocial factors affecting medication adherence in intimate partnerships, surveyed a clinic sample of mixed status couples in New York City (Wagner et al., 2002). The authors reported that higher adherence was associated with the HIV-negative partner attributing less risk to unprotected anal or vaginal sex within the couple ($r$ = 2 0.36, $p$< 0.05). Wagner and colleagues suggest that this perception may be linked to the belief that increased adherence results in reduced viral load and therefore reduced risk of viral transmission through unprotected sex. Consequently, the idea that unprotected sex will be possible if adherence is maintained works as a positive reinforcer within the couple. However, six couples who reported engaging in unprotected vaginal or anal sex in the past two months had significantly lower adherence than other couples ($t$ =4.365, $p < 0.001$). The correlational design of this study may reduce the validity of the claims made in this paper. While correlational studies can suggest a relationship between two variables, they cannot prove that one variable causes a change in another variable; this change may be caused by other factors not assessed within the study.

Skovdal et al. (2011), Wrubel et al. (2008) and Wrubel et al. (2010) utilised qualitative methodologies to explore the support practices of men in heterosexual couples in Zimbabwe (Skovdal et al., 2011) and men in same-sex couples in the United States (Wrubel et al., 2008; Wrubel et al., 2010). Skovdal and colleagues conducted 37 individual interviews and 5 focus groups with PLWH and HIV nurses in rural eastern Zimbabwe. The study aimed to explore how male denial of HIV, through the concept of hegemonic masculinity, impacts on female partner’s ability to access and adhere to ART. Findings suggested that men saw HIV as a threat to their manhood and dignity and demonstrated a profound fear of the disease. Social constructions of masculinity resulted in men perceiving illness as a weakness. Men therefore denied or avoided their association with HIV and also undermined their partner’s efforts to access and adhere to ART. Women felt unable to disclose their HIV status to their husbands, resulting in the women taking their medication in secret, and forgoing the support of a treatment partner. Some accounts told of how men, upon discovering that their partners were on ART, refused them permission to take the drugs, or stole the drugs for their own HIV treatment.

In the United States, Wrubel and colleagues (Wrubel et al., 2008; Wrubel et al., 2010) found evidence for more supportive relationships between male same-sex serodiscordant and seroconcordant couples. These two papers involving the same sample aimed to describe the practical support offered for ART adherence by partners of men with HIV, and latterly to understand when, why and how support is offered and received and how this impacted on adherence.  Three forms of practical support were identified. Support through reminding was a key mechanism to help PLWH take their medication. This was split into three different types of reminding: regular reminding, e.g. when meds due; situational reminding, e.g. when new med regime; and intensive reminding, e.g. nagging. Instrumental help was also seen as a useful support. This took shape in four forms: monitoring medications, for example checking; bringing medication to the partner or setting out medication; organising medication, for example in a medication box; and finally ordering and getting medication refills, e.g. from the pharmacy. The final form of practical support took a more motivational role in the form of coaching, for example situational problem solving or shaping behaviour by reinforcing incremental gains and offering affirmations.

To summarise, males and females may differ in the type of support they seek or the type of support that maintains higher levels of adherence (Knowlton, 2011a; Knowlton, 2011b). Men may prefer the support of someone other than their female partner (Knowlton, 2011b). Conversely, having an HIV positive partner may reduce the likelihood for women of being able to adhere to treatment, particularly if there is substance misuse within the couple (Knowlton, 2001a). Also for women, the impact of intimate partner violence could indicate a reduced ability to adhere to medication. Furthermore, if substance use is used as a coping method in intimate partner violence, then both men and women are likely to have difficulties adhering to medication. Whilst four of the five quantitative studies measured depressive symptoms in the participants (Knowlton, 2011a; Knowlton, 2011b; Wagner et al., 2002; Do et al., 2010), only three found significant results for an association between depression and non-adherence. The reasons for these outcomes are not addressed in the research but would suggest the need to explore further psychological constructs relating to distress, self-efficacy to adhere, or avoidant coping strategies.

The remaining studies cover a broad area and suggest that behavioural principals have an impact on medication adherence, for example expectations about unprotected sex (Wagner et al., 2002) and types of supportive help (Wrubel et al., 2008; Wrubel et al., 2010). Finally, the issues of gender roles and the impact this has on adherence for women in Africa provided a unique insight into the difficulties for couples in resource limited settings that have high stigma attached to a diagnosis of HIV.

These papers provide a small snapshot into the impact of intimate partners on medication adherence; however, the research in this area is scarce and covers a broad area of interest making it difficult to draw conclusions. Therefore, whilst it is clear that the evidence suggests a link between the presence or absence of positive intimate partner support and mediation adherence – particularly when substance misuse and intimate partner violence is implicated - it is not clear what mediates these links for different populations of people affected by HIV.

**Question 2 - Who else supports people on HIV medication and how do these supportive practices impact on medication adherence?**

A total of eight studies were identified in the literature search that focused on the relationship between wider social support, including family, friends and treatment supporters, and medication adherence.

Utilising the UCLA Social Support Inventory, three studies indicated a link between perceived satisfaction with social support and medication adherence (Simoni et al., 2002; Power et al., 2003; Simoni et al., 2006). Similarly, using perceived social support as a variable Gardenier et al. (2010) aimed to compare adherent and non-adherent PLWH with co-morbid depressive symptoms. Two studies aimed to describe the characteristics and experiences of being a treatment supporter (Foster et al., 2010; Marino et al., 2007). Finally, two studies conducted within ‘medicine companion’ clinics in South Africa (Nachega et al., 2006) and Mozambique (Stubbs et al., 2009) aimed to understand the impact of medicine companions at different stages of taking ART medication.

Simoni and colleagues (2002) conducted mediation analyses to determine rates and correlates of adherence and social support. Their findings indicated that a perceived need for social support was positively correlated with acknowledged non-adherence; this relationship was mediated by reduced self-efficacy in taking ART medication and greater depressive symptoms. Furthermore, the authors suggested that those who needed support from an affirming other, an information-enhancing relationship, and an empathic listener or from spiritual relationships were less likely to achieve greater adherence. A later study by Simoni and colleagues (2006) investigates a cognitive-affective model of medication adherence based on social support theory and research. The authors found at baseline that social support was associated with less negative affect and greater spirituality, which, in turn, was associated with self-efficacy to adhere. Self-efficacy to adhere at baseline predicted self-reported adherence at 3 months, which predicted favourable viral load at 6 months. Therefore, although social support was not directly related to adherence, it did have an indirect effect through reduced negative affect (stress, anxiety & depression), increased spirituality and self-efficacy to adhere. Using the same measure of social support, Power and colleagues (2003) suggested  that perceived satisfaction with support from a partner was associated with taking antiretroviral therapy as prescribed, whereas satisfaction with support from friends and from family was not significantly related to adherence.

A study investigating differences between adherent and non-adherent PLWH with co-morbid mental health distress, substance use, or adjustment issues found a positive correlation between adherence and overall social support (Gardenier et al., 2010). Those in the adherent group reported higher levels of overall social support; though this was a relatively weak correlation. When examined more closely, scores in both groups were higher for perceived satisfaction with practical support than they were for emotional support, potentially reflecting the professional support and assistance received from the day centre from the study recruitment site. Adherent participants also had a significantly higher number of CD4 cells, suggesting that treatment was having a beneficial effect on the immune system. Those in the adherent group also felt a stronger sense of belonging to a group with similar interests and concerns; however, this was not elaborated further to understand to whom this related. Of note is the correlation of adherence with ‘recognition of one’s abilities and competence’, suggesting that the adherent group may have had a higher self-efficacy to adhere.

A small number of studies explored the characteristics or experiences of being a medicine companion (Foster et al., 2010; Marino et al. 2007). Using mixed qualitative and quantitative methods in Uganda, Foster and colleagues (2010) found that women taking ART were more likely to choose a child to be their medicine companion whereas men were more likely to choose their spouse. Qualitative responses revealed that medicine companions were chosen for convenience, reliability and trust. Medicine companions were perceived to be most useful in the first 3 months of treatment for reminders and support but less useful after 6 months. Marino et al. (2007) asked peer supporters about their experiences of providing support to ART recipients. Peers reported that receiving information about HIV, medication and community services from other peers lessened their own fears and uncertainties. They also reported that through their role as helpers they began to feel more personally empowered. They felt more comfortable talking about their disease, and experienced a change in outlook. They also described a change in outlook in relation to themselves, their environment and HIV.

Two further studies conducted with clinics employing a medicine companion approach to ART delivery aimed to understand the impact of medicine companions at different stages of taking ART medication. (Nachega et al., 2006; Stubbs et al., 2009). Nachega and colleagues interviewed 11 women and 1 man in a township of South Africa where participants identified the critical forms and sources of support that facilitate adherence and the perceived social and material barriers to adherence. In the short term (< 3 months) a focus on medical aspects of HIV was perceived to be of key importance. Conversely, long term support focused on empowered living and maintaining adherence, and having necessary motivation, knowledge and support to sustain optimum adherence. Medicine companions tended to be a mix of healthcare providers, social workers, church members and family members. Proximity to the PLWH was a key characteristic of choosing a medicine companion. Disclosure was recognised as a key step in building supportive adherence relationships; however, there were social barriers to disclosure and stigma that sometimes prevented disclosure.

The final study in this review relating to wider social support aimed to evaluate the association between type of medicine companion (either a community-based trained activist , self-selected family members or friends, or no medicine companion) and adherence to HAART in the first 6 months of treatment (Stubbs et al., 2009). In adjusted analysis, patients who had no treatment partner were more likely to have low adherence (compared to self-selected treatment partner). Patients with community-based treatment partners did not have significantly lower adherence than patients with self-selected treatment partners.

In summary, the papers in this review support the notion that a perceived or lack of tangibly received social support can adversely affect medication adherence (Ammassari et al., 2002). It is reasonable to consider that the presence of instrumental and emotional support from someone in the social network can reduce barriers and increase motivation to adhere. There is also reasonable evidence that reduced self-efficacy, greater depressive symptoms and poor social support are related to sub-optimal adherence but this relationship is not explored further in these studies and thus remains poorly understood. There is little published research on the characteristics and utility of medicine companions from the perspective of PLWH. However, when choosing a medicine companion it would appear that it needs to be someone with whom the PLWH can trust and who can support them through the initial stages of beginning ART. This person can equally be a child, a family member or a community activist, but having no treatment partner is clearly related to lower levels of adherence. It would appear that wider social support may be equally as efficacious as intimate partner support.

### Question 3 - Are interventions aimed at intimate partner support or wider social support efficacious in increasing adherence to HIV medication?

A total of six papers were identified in the literature search that assessed associations between the influence of intimate partners or social support and adherence outcomes. Across the six papers there is wide variation in approach and content with only one paper specifically involving intimate partners in the intervention (Remien et al., 2005). Of the remaining papers, one study sampled HIV positive African-American women to assess the impact of an intervention to reduce familial stress, and thus increase adherence (Feaster et al., 2010). Three studies involved the recruitment of supportive treatment partners (Koenig et al., 2008; Simoni et al., 2007; Taiwo et al., 2010). The remaining study assessed the efficacy of a cognitive behavioural intervention on adherence (Murphy et al., 2002). This study was the only paper that did not directly involve treatment partners in their study; however, social support was a key dependent variable. Five of the studies were conducted in the United States (Remien et al., 2005; Feaster et al., 2010; Murphy et al., 2002; Simoni et al., 2007; and Koenig et al., 2008) and one study was conducted in Nigeria (Taiwo et al., 2010).

Adherence during these studies was measured in two ways. Firstly, two papers (Remien et al., 2005; Koenig et al., 2008) measured adherence with a MEMS cap. One study utilised both MEMS and self-report (Simoni et al., 2007) and two further studies measured adherence from self-report alone (Feaster et al., 2010; Murphy et al., 2002). The final study measured adherence using data from pharmacy pick-up records (Taiwo et al., 2010); therefore this data only records if the medication was picked-up by the patient, but not if they actually took the medication. Medication adherence was generally measured as the percentage of doses taken as prescribed, including dosage and time taken.

Five of the six studies reported increases in adherence; however, the levels of adherence and the maintenance of these levels differed between studies. The only couples-based intervention reported significantly improved medication adherence compared to usual care, although adherence for many participants was still suboptimal (<95%); however, these effects diminished over time (Remien et al., 2005). Remien et al. compared standard care treatment to an intervention aimed at improving patients' adherence to ART medication by utilising the support of their intimate partners in the treatment process. All couples were serodiscordant couples, heterosexual or homosexual, although there was no report of the proportions of each sexuality category. All patients were categorised as non-adherers with less than 80% adherence rates at baseline. The social action approach (Ewart, 1991) within the intervention aimed to give emphasis to social interdependence within the couple and interaction in personal control of adherence behaviour using communication and problem solving strategies. Intention to treat analyses indicated that the patients in the intervention condition showed higher mean medication adherence when compared to the control group. The results were significant in both the proportion of doses taken (76% and 60% respectively) and doses taken in specified time window (58% and 35% respectively) at eight weeks post-intervention. However, these effects diminished over the follow-up period, at 12 weeks and 26 weeks. Forty-seven per cent of participants (n=50) in the intervention group also had adherence of greater than 90% at week 8, 2 weeks post-intervention. However, whilst adherence was increased in the intervention group, at 6 months the mean adherence rate of 66% of doses taken is below the optimum 95% stated in the clinical guidelines for the sustained suppression of HIV in the body and to prevent viral resistance to medication. This lower level of overall adherence possibly explains the non-significant findings for an association between adherence and reductions in viral load across the sample. The remaining studies utilised wider social support systems in aiming to increase medication adherence.

In a study using a systemic based intervention, Feaster et al. (2010) reported that Structural Ecosystems Therapy (SET) involving family members attending therapy to reduce ‘family hassles’, was significantly more likely to move women towards high levels of adherence (at least 95%) than the person-centred treatment (PCA) condition (Odds ratio1.45, 95% CI [1.04-2.01]). Over time, women in the SET group demonstrated increased probability of being > 95% adherent, whereas women in the PCA group showed decreased probability of being in >95% adherent. The control condition also demonstrated a decline in the probability of maintaining >95% adherence. However, this was not significantly different from the other two groups. Family hassles were significantly reduced by SET but the effect of SET on adherence did not seem related to the change on family hassles; therefore this variable was not supported as a mediator as initially hypothesised. This study employed a small sample size (n=127) with no information reported on the numbers or characteristics of participants in the intervention or control arms. In terms of who was chosen to attend the social support intervention, participants’ children were most often in attendance at family therapy sessions,  followed by ‘significant others’, siblings, extended family, healthcare workers and finally, friends. No data were reported on the number, characteristics, or satisfaction with these social supporters.

Simoni et al. (2007) recruited peer mentors from within an HIV service, who were recognised as ‘good’ adherers, to provide a social support intervention involving support groups and telephone contacts compared with standard clinical care. The authors found no between-conditions intervention effects on the outcomes of adherence, social support or depressive symptoms at immediate post-intervention or follow-up. However, post hoc analyses within the intervention condition indicated that greater intervention exposure, or a larger number of sessions attended, was associated with higher self-reported adherence, higher social support, and lower depressive symptomatology at follow-up, even after controlling for baseline adherence. This study employed treatment supporters chosen by the clinicians, not the participants; they provided a broadly behavioural and affective intervention over a 3-month period. Whilst the peers provided weekly telephone calls to the participants, it is likely that the lack of proximity to the participant weakened the effects of the intervention - other studies reviewed here had supporters living in the same house. The sample size was also under-powered, which may have influenced the statistical significance of the findings (Type II error) with a larger sample size perhaps producing significant findings.

Two of the six studies recruited participants who were not currently taking ART medication. One of these was conducted in Nigeria assessing the effectiveness of ‘patient-selected treatment partners’ (Taiwo et al., 2010). At week 24, undetectable viral load was achieved by 61.7% of patients in the Treatment Partner Assisted (TPA) arm versus 50.2% of those receiving standard care (SOC, p=0.05). However there was no significant difference at week 48 (65.3% for TPA and 59.4% for SOC).

The TPA group had more than 3 times the odds of at least 95% drug pick-up adherence through week 24 and almost twice the odds after week 48. Therefore, the use of patient-selected treatment partners was associated with improved drug pick-up adherence and initial virologic success but had no durable effect on attaining undetectable viral load.

The second of these studies utilised an intervention to recruit supportive treatment partners in the first six months of ART prescribing. In this study significantly higher adherence was reported in the intervention group compared to the standard care adherence counselling group (Koenig et al., 2008). However, these effects also diminished with time. The intervention drew on Problem Solving Theory and a five-stage model of problem solving training, which is broadly cognitive in nature (Johnson, Elliott, Neilands, Morin, & Chesney, 2006). The initial sample size was relatively small. There were also high attrition rates with 38% of participants lost to follow-up by the six-month point; these individuals were assumed to be non-adherent in the intent-to-treat analyses. There was no description of the treatment supporters chosen by study participants; they are described in the introduction as ‘friends and family members’. Therefore, it is not possible to ascertain if these were intimate partners or family members who lived in the same household as the participant.

Utilising a CBT intervention, Murphy et al. (2002) found no significant differences in adherence for the intervention group compared to the control group. The author stated that perhaps being part of a trial increased adherence for both intervention and control groups. This study employed a very small sample size (n=33), with 17 participants in the intervention group and 16 in the control group. This small sample size increases the chance of a Type II error. Secondary benefits of increased levels of social support immediately following the intervention were noted, as measured in/by a social support questionnaire. However, these effects were relatively weak (p= 0.4). Murphy et al. stated that the reasons for social support increases could be due to the supportive nature of the group-format session or the relationship built with the CBT therapist. This study does not state baseline demographic data for the each group; thus it is not possible to determine if both groups were matched and thus equal at baseline.

In summary, interventions from behavioural, systemic or cognitive behavioural backgrounds aimed at involving a supportive partner appear to demonstrate some benefits in improving HIV medication adherence. However, these effects appear to be transitory, with adherence rates diminishing with time. This reduction in adherence suggests the need for booster sessions or interventions that have more durable effects. Whilst the studies included in this review have a similar focus- the effects of social support on adherence- they cover a wide variation in theoretical and methodological approach and content. The length and intensity of the interventions reviewed vary considerably. These issues raise challenges in making comparisons and allow only tentative conclusions to be drawn. What is evident from these papers is that no differences were reported between any of demographic variables assessed, for example gender, sexuality, ethnicity and financial income, suggesting that the results of these studies are comparable across groups.

# DISCUSSION

This review aimed to present a systematic summary of research exploring the impact of intimate partner or social support on medication adherence. It would suggest that despite the varied and broad range of studies available for review there is some evidence to suggest that intimate partners and wider social support can directly or indirectly influence medication adherence.

The types of support given across the studies are wide-ranging and measured in various ways. It is clear that unhelpful support is present in relationships involving substance misuse and intimate partner violence, due to the chaotic and challenging behaviours that can develop in these relationships. Conversely, the impact of usefully perceived social support on improvements in adjustment, depression and adherence is consistent with previous research investigating intimate partner violence in substance misusing relationships (Coker et al., 2002) and chronic physical health problems (Reinhardt et al., 2006: Martire et al., 2010). Therefore, studying individuals who are in need of help is important, particularly when examining the effect of received support on adherence and comparing its effect with perceived support.

Interventions to improve adherence utilising a member of the patient’s support network or measuring perceived satisfaction with support show promising results. There were small improvements with adherence following exposure to interventions, unfortunately these effects diminished over time. This suggests the need to further investigate the mechanisms involved or assess the need for on-going social support based intervention, perhaps including supporters in the patients care over a longer period of time.

The universal generalisation of the results of these studies is also problematic, firstly because most studies take place in idiosyncratic samples in the United States, suggesting a possible lack of generalisability to the UK.  Secondly, study participants frequently represented convenience samples taken from clinic populations. Therefore, this review continues to leave questions unanswered that might exist for clinicians, service managers and researchers in the field. It is hoped that by uncovering the gaps in the current evidence, future research will attempt to usefully address these questions.

### Quality of the evidence

A notable feature of the body of literature reviewed here is the lack of well controlled studies with rigorous methodological designs. Whilst six studies employed a control group and tested the efficacy of an intervention to increase medication adherence, the remaining eleven quantitative studies were observational in their approach. It is therefore sensible to cautiously consider the conclusions that some authors made when interpreting their findings from uncontrolled or observational studies and how these conclusions answer the current research questions.

Within the studies assessing factors related to intimate partners and medication adherence there was little attention given to the rationale for the an observational design (e.g. Wagner et al., 2002). Whilst in the intervention studies that utilised various types of control groups, there was a generally good rationale given for utilising this approach. Good descriptions were given for the recruitment and randomisation procedure, thus reducing bias and strengthening the significant findings (e.g. Koenig et al., 2008). These papers were of good quality and helped to answer the research questions with more confidence.

Evaluation of the qualitative papers included assessment of the credibility and reliability of the findings. Of the five papers that utilised a qualitative methodology only one study failed to describe how they addressed the issue of validity during the analysis and interpretation stages, for example through external reviewers, dual coders, or triangulation (Nachega et al., 2006). The remaining studies did use multiple coders to cross-validate themes and presented their findings using a number of participant quotations. In terms of reflectivity, not one study commented on the influence of the research process or the presence of the researcher on the data collected or resulting themes. Only one study used a writing style that suggested a subjective approach to the topic (Wrubel et al., 2010). However, these papers were useful in addressing aspects of intimate partner or wider social support that were not considered by the quantitative studies.

## Clinical Implications

This review suggests that considering partners and social support might be useful in increasing ART medication adherence for PLWH. For individuals who are socially isolated, social or peer support could increase the supportive mechanisms available for people who are experiencing adherence difficulties (Small, Taft & Brown, 2011).

This review also suggests a need for psychologists to better understand the links between therapeutic models and medication adherence. The studies in this review did not clearly state the rationale for using particular models in social support intervention for medication adherence. One avenue for exploration for example may be a psychodynamic approach (Malan & Coughlin Della Selva, 2006). The focus on defences, such as denial and avoidance, particularly PLWH who often have histories of trauma and stigmatisation may have some promise in helping individuals try to resolve their own unconscious conflicts over their illness (Ricart et al., 2002). The relational foundation of the psychodynamic approach can be applied to thinking about intimate partners or social support in medication adherence, for example considering the transference and countertransference issues involved in offered and received support (Sherr, 2000).

## Future Research

There are several potential implications from this review for researchers; the most important are presented here. Due to the limitations of the studies reviewed here and the difficulty in reaching a confident conclusion relating intimate partner and social support factors to adherence to ART, it would be useful to develop research that builds on the stronger papers in this review. One way to do this is to follow the suggestion above of providing a sound rationale for the use of particular psychological approaches as a foundation for intervention.  Previous researchers have also have noted that couple interventions are rarely conceptually driven nor do they often identify specific targets for change (Martire et al., 2007).

The differing measurement of adherence across studies in this review could also be improved upon by consistently using an adherence measure that is grounded in evidence (e.g. Chesney et al., 2000). In addition, the assessment of correlates of adherence is worthy of further investigation to explore in more detail the mechanisms of correlates such as depression or perceived support and its impact on self-efficacy to adhere and therefore adherence (Simoni et al.,2002).

## Limitations of Review

An important limitation of the review is the possibility of publication bias. Studies included in this review consisted on peer-reviewed studies and those that resulted from the literature search. It was thought these would be the most methodologically rigorous and thus yield the strongest conclusions. No attempt was made to conduct a forward search of papers that cited the studies in the review. Conference abstracts were excluded, thus research that is yet to be published remains unknown. The file drawer problem (Rosenthal, 1979), that research with null findings are much less likely to be published than research with statistically significant results, suggests that even greater caution is taken in drawing conclusions based on the published literature.

A second limitation is that the review could be subject to bias from the researcher. Although attempts were made to minimise bias by following checklists for data extraction and quality assessment, an element of bias in the interpretation of the study findings could exist.

## Conclusion

Research suggests that effective intimate partner or wider social support can lead to better adherence to treatment and to improved health outcomes. However, this review has demonstrated that there are few studies that systematically test this claim and fewer that report significant and enduring results on medication adherence. Therefore research on the types of partner or social support that have shown promise in increasing adherence is needed to further develop this evidence base.

# REFERENCES

Ammassari A, Trotta MP, Murri R, Castelli F, Narciso P, Noto P, Vecchiet J, D'Arminio Monforte A, Wu AW, Antinori A; AdICoNA Study Group. (2002) Correlates and predictors of adherence to highly active antiretroviral therapy: overview of published literature. *J Acquir Immune Defic Syndr*. 15;31 Suppl 3:S123-7. Review.

Caldwell, K., Henshaw, L., & Taylor, G. (2005). Developing a framework for critiquing health research. *Journal of Health, Social and Environmental Issues, 6* (1), 45-54.

Coker, A.L., Smith, P.H., Thompson, M.P., McKeown, R.E., Bethea, L., Davis, K.E. (2002). Social support protects against the negative effects of partner violence on mental health*. J Womens Health Gend Based Med.11*:465–476. doi: 10.1089/15246090260137644.

Chesney, M., Ickovics, J., Chambers, D., Gifford, A., Neidig, J., Zwickl, B., Wu, A.W. (2000). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: The AACTG adherence instruments. *AIDS Care, 12*,255-266.

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika, 16,* 297-334.

Critical Appraisal Skills Programme (CASP), (2006). Retrieved January 5, 2012 from Public Health Resource Unit, http://www.caspinternational.org/?o1020

Delaney, M. (2006). History of HAART-the true story of how effective multi-drug therapy was developed for treatment of HIV disease. *Retrovirology*, 3(1):S6 doi:10.1186/1742-4690-3-S1-S6

Do, N. T., Phiri, K., Bussmann, H., Gaolathe, T., Marlink, R. G., & Wester, C. W. (2010). Psychosocial Factors Affecting Medication Adherence Among HIV-1 Infected Adults Receiving Combination Antiretroviral Therapy (cART) in Botswana. *AIDS Research and Human Retroviruses*, 26(6), 685-691. doi:10.1089/aid.2009.0222

DiMatteo, M.R. (2004). Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis. *Health Psychology 23*, 2, 207–218

Eldred, L. (1997). *Adherence in the era of protease inhibitors.* John Hopkins HIV Report. Baltimore, MD: John Hopkins University AIDS Service.

Ewart, C.K. (1991) Social action theory for a public health psychology. *American Psychologist*, 46(9), 931-946.

Feaster, D.J., Brincks, A.M., Mitrani, V.B., Prado, G, Schwartz, S.J., & Szapocznik, J. (2010). The Efficacy of Structural Ecosystems Therapy for HIV Medication Adherence With African American Women. *Journal of Family Psychology*, *24*(1), 51-59.

Fogarty L, Roter D, Larson S, Burke J, Gillespie J, & Levy R. (2002). Patient adherence to HIV medication regimens: a review of published and abstract reports. *Patient Educ Couns.* 46: 93-108.

Foster S.D., Nakamanya S., Kyomuhangi R., Amurwon J., Namara G., Amuron B., … Grosskurth, H. (2010). The experience of "medicine companions" to support adherence to antiretroviral therapy: Quantitative and qualitative data from a trial population in Uganda. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 22, 35-43.

Fowkes, F.G.R., & Fulton, P.M. (1991). Critical appraisal of published research: introductory guidelines. *British Medical Journal 302,* 1136-1140

Gardenier, D., Andrews, C. M., Thomas, D. C., Bookhardt-Murray, L. J., & Fitzpatrick, J. J. (2010). Social Support and Adherence: Differences Among Clients in an AIDS Day Health Care Program. *Journal of the Association of Nurses in AIDS care*, 21(1), 75-85.

Goggin, K., Liston, R.J., & Mitty, J.A. (2007) Modified directly observed therapy for antiretroviral therapy: a primer from the field. *Public Health Rep*, 122:472–481.

Haug, N.A.,& Sorensen, J.L. (2006) Contingency management interventions for HIV-related behaviors. *Curr HIV/AIDS Rep*, 3:154–159.

House, J. S., & Kahn, R. L. (1985). Measures and concepts of social support. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 83–108). New York: Academic Press.

Ickovics, J. R. & Meisler, A. W. 1997 Adherence in AIDS clinical trials: a framework for clinical research and clinical care. *J Clin. Epidemiol. 50*, 385^391.

Johnson, M., Elliott, T., Neilands, T., Morin, S., & Chesney, M. (2006). A social problem-solving model of adherence to HIV medications. *Health Psychology, 25,* 355–363.

Kaul, M., & Lakey, B. (2003). Where is the support in perceived support? The role of generic relationship satisfaction and enacted support in perceived support's relation to low distress. *Journal of Social and Clinical Psychology*, *22*, 59–78.

Kelleher, A. D., Carr, A., Zaunders, J., & Cooper, D. A. (1996). *Journal of Infectious Diseases.* 173, 321-9.

Knowlton, A. R., Yang, C., Bohnert, A., Wissow, L., Chander, G., & Arnsten, J. A. (2011a). Informal Care and Reciprocity of Support are Associated with HAART Adherence Among Men in Baltimore, MD, USA. *AIDS and Behaviour* 15:1429–1436

Knowlton, A. R., Yang, C., Bohnert, A., Wissow, L., Chander, G., & Arnsten, J. A. (2011b). Main partner factors associated with worse adherence to HAART among women in Baltimore, Maryland: a preliminary study. *AIDS Care*, *23*, 1102-1110. doi:10.1080/09540121.2011.554516

Koenig, L.J, Pals, S. L., Bush, T., Pratt, P. M., Stratford, D., & Ellerbrock, T.V. (2008). Randomized controlled trial of an intervention to prevent adherence failure among HIV-infected patients initiating antiretroviral therapy. Health Psychology: *Official Journal of the Division of Health Psychology, American Psychological Association*, 27(2), 159-169.

Liu, H., Golin, C.E., Miller, L.G., Hays, R.D., Beck, K.C., Sanandaji, S.,...Wenger, N.S. (2001). Comparison study of multiple measures of adherence to HIV protease inhibitors. *Ann Intern Med.* 134:968–77.

Lopez, E. J., Jones, D. L., Villar-Loubet, O. M., Arheart, K. L., & Weiss, S. M. (2010). Violence, Coping, and Consistent Medication Adherence in HIV-Positive Couples. *AIDS Education and Prevention*, 22(1), 61-68. doi:10.1521/aeap.2010.22.1.61

Malan, D., & Coughlan Della Selva, P. (2006) *Lives Transformed: A Revolutionary Method of Dynamic Psychotherapy.* London, England. Karnac.

Martire, L., Schulz, R., Keefe, F., Rudy, T., & Starz, T. (2007). Couple-oriented education and support intervention: Effects on individuals with osteoarthritis and their spouses. Rehabilitation Psychology, 52, May07-132.

Marino, P., Simoni, J.M., & Bordeaux-Silverstein, L. (2007). Peer support to promote medication adherence among people living with HIV/AIDS. *Social Work in Health Care, 45*:1, 67-80

Murphy, D.A., Greenwell, L. & Hoffman, D. (2002). Factors associated with antiretroviral adherence among HIV-infected women with children. *Women and Health*, 36, 97-111.

Murphy, D. A., Lu, M. C., Martin, D., Hoffman, D., & Marelich, W. D. (2002). Results of a pilot intervention trial to improve antiretroviral adherence among HIV-positive patients. *The Journal of the Association of Nurses in AIDS Care*: JANAC, 13(6),

Nachega, J. B., Knowlton, A. R., Deluca, A., Schoeman, J. H., Watkinson, L., Efron, A., … Maartens, G. (2006). Treatment Supporter to Improve Adherence to Antiretroviral Therapy in HIV-Infected South African Adults. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 43(Supplement 1), S127-S133.

Nieuwkerk, P.T, & Oort, F.J.(2005). Self-reported adherence to antiretroviral therapy for HIV-1 infection and virologic treatment response: a meta-analysis. J Acquir Immune Defic Syndr 2005; 38: 445–8.

Pendley, J.S., Kasmen, L.J., Miller, D.L., Donze, J., Swenson, C., Reeves, G. (2002) Peer and Family Support in Children and Adolescents With Type 1 Diabetes. *Journal of Pediatric Psychology;*. 27(5):429-438.

Power, R., Koopman, C., Volk, J., Israelski, D. M., Stone, L., Chesney, M. A., & Spiegel, D. (2003). Social Support, Substance Use, and Denial in Relationship to Antiretroviral Treatment Adherence among HIV-Infected Persons. *AIDS Patient Care and STDs*, 17(5), 245-252.

Rea, M.M., Miklowitz, D.J., Tompson, M.C., Goldstein, M.J., Hwang, S., Mintz, J. (2003) Family-focused treatment versus individual treatment for bipolar disorder: results of a randomized clinical trial. *J Consult Clin Psychol*; 71:482–492.

Reinhardt, J.P., Boerner, K., & Horowitz, A. (2006) Good to have but not to use: Differential impact of perceived and received support on well-being*. Journal of Social and Personal Relationships* 23: 117

Remien, R, H., Stirratt, M. J., Dolezal, C., Dognin, J.S., Wagner, G, J., Carballo-Dieguez, A., El-Bassel, N., Jung, T.M. (2005) Couple-focused support to improve HIV medication adherence: a randomized controlled trial. *AIDS*. 19, 807-814.

Ricart, F., Cohen, M.A., Alfonso, C.A., Hoffman, R.G., Quinones, N., Cohen, A., & Indyk, D. (2002). Understanding the psychodynamics of non-adherence to medical treatment in persons with HIV infection. *General Hospital Psychiatry 24* 176-180

Rosenthal, R. (1979). The file drawer problem and tolerance for null results. *Psychological Bulletin, 86*(3), 638-641.

Rueda, S., Park-Wyllie, L.Y., Bayoumi, A., Tynan, A-M., Antoniou, T., Rourke, S., Glazier, R. (2006) Patient support and education for promoting adherence to highly active antiretroviral therapy for HIV/AIDS. *Cochrane Database Syst Rev* 2006, 3:CD001442.

Safren, S.A., O'Cleirigh, C.M., Bullis, J.R., Otto, M.W., Stein, M.D., Pollack, M.H. (2012) Cognitive Behavioral Therapy for Adherence and Depression (CBT-AD) in HIV-Infected Injection Drug Users: A Randomized Controlled Trial. *Journal of Consulting & Clinical Psychology*. 80(3):404-415..

Sale, J. E. M., & Brazil, K. (2004). A strategy to identify critical appraisal criteria for primary mixed method studies. *Quality & Quantity, 38,* 351-365.

Sherr, L. (2000) Adherence: sticking to the evidence. *AIDS Care 12* (4) 373-375.

Simoni, J. M., Frick, P. A., Lockhart, D., & Liebovitz, D. (2002). Mediators of social support and antiretroviral adherence among an indigent population in New York City. *AIDS Patient Care and STDs*, 16(9), 431-439.

Simoni, J. M., Frick, P. A., & Huang, B. (2006). A longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. *Health Psychology*, 25(1), 74-81.

Simoni, J. M., Pantalone, D. W., Plummer, M. D., & Huang, B. (2007). A randomized controlled trial of a peer support intervention targeting antiretroviral medication adherence and depressive symptomatology in HIV-positive men and women. Health Psychology: *Official Journal of the Division of Health Psychology, American Psychological Association*, 26(4), 488-495.

Small R, Taft AJ, Brown SJ. (2011).The power of social connection and support in improving health: lessons from social support interventions with childbearing women. *BMC Public Health 25*;11 Suppl 5:S4.

Skovdal M., Campbell C., Nyamukapa C. & Gregson S.. (2011). When masculinity interferes with women's treatment of HIV infection: A qualitative study about adherence to antiretroviral therapy in Zimbabwe.  *Journal of the International AIDS Society*, 14,

Stubbs, B. A., Micek, M. A., Pfeiffer, J. T., Montoya, P., & Gloyd, S. (2009). Treatment partners and adherence to HAART in Central Mozambique. *AIDS Care*, 21(11), 1412-1419.

Taiwo, B.O., Idoko, J. A., Welty, L.J., Otoh, I., Job, G., Iyaji, P.G.,… Murphy, R.L. (2010). Assessing the virologic and adherence benefits of patient-selected HIV treatment partners in a resource-limited setting. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *54*(1), 85-92.

Velleman, R., Templeton, L.J., Copello, A.G. (2005) the role of the family in preventing and intervening with substance use and misuse: a comprehensive review of family interventions, with a focus on young people. *Drug and Alcohol Review: 24* (2) 93–109

Wagner G.J., Remien R.H., Carballo-Dieguez A. & Dolezal C. (2002). Correlates of adherence to combination antiretroviral therapy among members of HIV-positive mixed status couples. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 14, 105-109

Wagner G.J., Kanouse, D.E., Golinelli, D., Miller, L.G., Daar, E.S.,Witt, M.D.,...Haubrich, R.H. (2006) Cognitive behavioral intervention to enhance adherence to antiretroviral therapy: a randomized controlled trial (CCTG 578). *AIDS*, 20:1295–1302.

Weber, B.A., Roberts, B.L., Resnick, M., Deimling, G., Zauszniewski, J.A., Musil, C., Yarandi, H.N. (2004). The effect of dyadic intervention on self-efficacy, social support, and depression for men with prostate cancer. *Psycho-Oncol; **13**:* 47-60.

Wrubel J., Stumbo S. & Johnson M.O.. (2008). Antiretroviral medication support practices among partners of men who have sex with men: A qualitative study. *AIDS Patient Care and STDs*, 22, 851-858. doi:10.1089/apc.2008.0037

Wrubel J., Stumbo S. & Johnson M.O.. (2010). Male same-sex couple dynamics and received social support for HIV medication adherence. *Journal of Social and Personal Relationships*, 27, 553-572. doi:10.1177/0265407510364870

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# HOW DO WOMEN WITH BREAST CANCER AND THEIR MALE PARTNERS EXPERIENCE AND UNDERSTAND SEXUAL INTIMACY AND BODY IMAGE FOLLOWING SURGERY AND RECONSTRUCTION?

**by**

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# ABSTRACT

## Objective

Breast cancer treatment can have a profound impact on women's body image and sexual functioning. Furthermore, intimate partners feel this impact too. There is limited existing in-depth research on how a woman experiences and understands her body and experiences of sexual intimacy following a mastectomy with immediate reconstruction. Even less is known about how the male partners experience and make sense of this process and how the couple's views fit together. This study aims to gain a better understanding from the couples' perspective, of their experiences of breast cancer surgery and the impact on body image and sexual intimacy.

## Method

In this qualitative design, semi-structured interviews (n=8) were conducted with four couples where the female had undergone mastectomy with reconstruction following a diagnosis of breast cancer. The interviews explored experiences around diagnosis of cancer, decision making and experiences of body image and sexual intimacy post-surgery and into recovery.

## Results

The interviews were analysed using interpretative phenomenological analysis (IPA) which yielded three super-ordinate themes: 'Cancer as a central threat', 'The body becomes a central concern', and 'Centrality of communication'. These themes fitted within a process for each couple that was dynamic and changeable, with the focus changing from cancer to the female body, then moving again to focus on building relationships.

### Conclusions

This study illustrates the positive acceptance partners express towards their wives’ post-surgery bodies. This study also highlights the importance of communication and managing surgical expectations during the breast reconstruction process. The theoretical, clinical and research implications are discussed.

**Keywords**: Breast cancer, mastectomy, partners, women, body image and sexuality

# INTRODUCTION

In the UK approximately 46,000 people are diagnosed with breast cancer annually. Eighty percent of cases occur in women over the age of 50 with the disease being the most commonly diagnosed cancer in women under 35 (http://www.breastcancercare.org.uk). Despite the high incidence of breast cancer, the early detection through screening and the availability of high quality treatment means that survival rates are high. The estimated relative twenty-year survival rate for women with breast cancer has increased from 44% in the early 1990s to 64% in 2005 (Office for National Statistics, 2005).

## Breast cancer treatment

Breast cancer treatment typically involves surgery to remove the cancerous tissue, which can include the whole breast area (mastectomy) or part of the breast (lumpectomy). Adjuvant treatment such as chemotherapy or radiotherapy can also be an option to reduce the tumour prior to surgery or prevent its reoccurrence. Reconstructive surgery is an option for those who undergo a mastectomy, either at the time of the mastectomy (immediate reconstruction) or at a later date (immediate-delayed or delayed reconstruction). Reconstruction can take place with the woman's own healthy body tissue, an implant to replace all or some of the breast tissue, or a combination of both. Guidance from NICE (National Institute for Health and Clinical Excellence, 2009) state that clinicians should ensure that women should be offered a full range of appropriate reconstructive options, whether or not these are available locally.

In the 2011 audit of the provision and outcomes of mastectomy and breast reconstruction surgery in the UK, 21% of women had a mastectomy with immediate reconstruction, the majority opting for a mastectomy without reconstruction (69%). Nine out of ten women in the Audit felt that they had received the right amount of information about their chosen type of surgery (mastectomy alone, immediate reconstruction or delayed reconstruction). Ninety per cent of women were satisfied with the information they received pre-operatively on their surgical procedure (how it was performed, recovery time, and possible complications). However, only 50% of women were very satisfied with the information they received on what postoperative pain to expect, how long it would take “to feel normal again”, how much pain to expect during recovery and what their scars would look like (NHS Information Centre, 2011).

These findings are in line with NICE guidance, which states that when there is a choice between treatments, the information given must be sufficiently clear and detailed to allow the woman to make a decision based on evidence of differences in outcome (NICE; National Institute for Health and Clinical Excellence, 2009). This also highlights the importance of women making decisions about treatment that are well informed and perceived to be a good fit for their current circumstances.

### Breast reconstruction and outcomes

The range of reconstruction options available following a mastectomy presents women with a plethora of information to take into consideration whilst making a decision. This process is compounded by the short time in which they often have to make the decision as surgery is often needed quickly. From a clinical perspective, it was previously believed that a delayed reconstruction was more beneficial than immediate reconstruction, allowing time to ‘grieve’ for the lost breast, resulting in the reconstructed breast being accepted more readily (Winder & Winder, 1985). More recently, with advances in surgical procedures, the choice of an immediate reconstruction is thought to demonstrate a positive adjustment to breast cancer diagnosis and offers greater psychological benefits (Rowland, Diosso, Holland, Chaglassian, & Kinne, 1995). However, for women an important feature in the choice of mastectomy has been a fear of the recurrence of the cancer (Molenaar et al., 2004), while a major factor in deciding on breast reconstruction or conservation with a lumpectomy was concern about the cosmetic results (Temple et al., 2006). Research has therefore demonstrated that discussing treatment options with women, including immediate reconstruction, and involving patients in the decision-making process can improve outcome satisfaction and reduce psychological morbidity (Ananian et al., 2004; Heller, Parker, Youssef, & Miller, 2008; Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002).

In a UK based audit of breast surgery outcomes (NHS Information Centre, 2011), 90% of women who had an immediate reconstruction were satisfied with the outcome of surgery in terms of how they looked in the mirror clothed, while 59% were satisfied with how they looked in the mirror unclothed. This lower level of satisfaction in private may have a dramatic impact on physical intimacy. Conversely, studies examining the impact of these procedures on women’s body image and sexual functioning are scarce, and those that have been published report mixed results.

## Breast cancer, body image and sexuality

Body image relates to the mental image a woman has of her physical self and is closely linked with self-concept, attractiveness, self-confidence, self-esteem and sexuality (Harcourt & Rumsey, 2001). It has been stated that around 60% of women with a partner will continue to be sexually active following a diagnosis of cancer (Bloom, Stewart, Chang & Banks, 2004; Berglund, Nystedt, Bolund, Sjoden, & Rutquist, 2001) and that 52% of women report being satisfied with their sex-lives most or all of the time following breast cancer treatment (NHS Information Centre, 2011). Therefore, body image and sexuality are important issues for couples following diagnosis and treatment of breast cancer. This is further complicated by, the type of breast cancer treatment a woman undergoes and its potential to profoundly affect body image and sexuality. Chemotherapy can temporarily cause side effects such as hair loss, fatigue, weight gain, nausea, dryness of the vagina and loss of sexual desire. Among premenopausal women, chemotherapy can induce a premature and abrupt menopause due to its effects on the ovaries, with associated symptoms that can interfere with sexual functioning (Burwell, Case, Kaelin & Avis, 2006).

When investigating body image and adjustment to early stage breast cancer Carver et al. (1998) found that surgical treatment for cancer resulted in the deterioration of feelings of sexual desirability, and to feelings of alienation from the self. The authors also found that women who were concerned about their body image were more vulnerable to poor psychosocial adjustment following treatment for breast cancer, particularly for women who undergo mastectomy with reconstruction. A further study comparing physical and emotional outcomes of surgery found that women who had undergone a mastectomy with reconstruction were more likely to report a negative impact on their sex lives compared with those who underwent a lumpectomy or mastectomy without reconstruction (Rowland et al., 2000). Similarly, Yurek, Farrar and Andersen (2000) also reported that women who underwent a mastectomy with reconstruction reported reduced sexual activity compared to other surgery types. This research highlights the effects different surgery types can have on female body image and sexuality. It particularly demonstrates the need to understand the experiences of women who undergo a mastectomy with immediate reconstruction.

## The impact of breast cancer on intimate sexual relationships

Women's perceptions of partner beliefs have been shown to have an impact on sexual functioning and body image. Wimberly, Carver, Laurenceau, Harris, & Antoni (2005) found that women who felt their partners were not disturbed by their surgical scars during the early sexual experiences after surgery reported greater feelings of femininity and attractiveness. There was also an indication that a partner's emotional involvement was a strong predictor for a woman's sexual, marital, and emotional adjustment after breast cancer. Furthermore, Bukovic et al. (2005) reported that women found their partners' attitude towards them sexually to be the same or even better after treatment. Conversely, Anllo (2000) reported that changes in body image, sexual dysfunction, fears of cancer recurrence, and mortality could increase a woman's fear of rejection by their partner. In a small scale qualitative study (Holmberg, Scott, Alexy & Fife, 2001) women's perceptions of their partners' responses to questions around sexual desire were that it remained unchanged; however, the men indicated that they had experienced a decrease in sexual desire. The men unanimously believed that in the initial stages of diagnosis and treatment, sex was a minor issue in comparison to the potential death of their partners. In a qualitative study sampling women and their partners (Sheppard & Ely, 2008) the authors discovered narratives that women may wrongly perceive their partners to be repulsed and disturbed by changes in the women's body. The above research reminds us that discrepancies can exist between the views of the woman and the partner in intimate relationships and can therefore be a barrier to intimacy and sexual functioning.

### Partner focused research

Few studies have focused exclusively on the well partner's views of post-treatment sexuality and body image. Within the studies that have been published much emphasis has been placed on understanding the impact of cancer, coping mechanisms used, relationship styles or process issues during treatment, and not specifically on their experiences of post-operative sexuality and perceptions of body image (for example, Fitch & Allard, 2007a; Harrow, Wells, Barbour, & Cable, 2008; Kadmon, DeKeyser-Ganz, Rom & Woloski-Wruble, 2008). A qualitative study focusing on men's perspectives of coping with breast cancer and chemotherapy (Hilton, Crawford & Tarko, 2000) found that in the theme of putting self on hold the men commented on their sexual functioning. Some men felt frustrated by a lack of activity whilst others were more accepting of not having sex. It appeared that for some men the loss of a breast for their wife did not impact negatively on their desire to be intimate, *"I see my wife.....not her breasts so there is no problem with intimacy"* stated one male participant. Conversely, Fergus and Gray (2009) identified a theme around coping with sexual disruption and how couples found the changes in their sex lives to be a major challenge. Male partners particularly found it difficult to retain intimacy and feelings of closeness without the usual sexual routines taking place - due to treatment side effects and the stress of having breast cancer. It was difficult for many couples to separate their sexual interaction from the illness.

## RATIONALE

Breast cancer treatment can have a profound impact on women's body image and sexual functioning. Furthermore, intimate partners who also have to adjust to a diagnosis of breast cancer and the effects of treatment feel this impact too. Previous research presents a mixed picture of the body image and sexual intimacy outcomes for women who undergo a mastectomy with immediate reconstruction. Whilst there is extensive quantitative research on the clinical outcomes of differing surgery types, there is limited in-depth research on how a woman experiences and understands her body and experiences of sexual intimacy following a mastectomy and immediate reconstruction. Even less is known about how the male partners experience and make sense of this process and how the couple's views fit together. Such gaps within the existing literature give grounds for employing a qualitative approach to research that captures detailed accounts of experiential processes during breast cancer surgery and recovery. Therefore, using a phenomenological methodology, this research aims to sensitively explore and understand couples 'lived experiences' of body image and sexuality to gain a further understanding of this process. This is part of a wider aim to help breast care teams prepare couples for breast cancer treatment and possible changes in intimacy and relationship functioning.

### Research Questions

This study was guided by the following research questions:

1. How do breast cancer patients perceive and understand their body image and desire for intimacy?
2. How do intimate partners make sense of and cope with changes in their partner's body and how do they perceive their partners body image?

3. What have been the intimate partners own experiences of the impact of breast cancer treatment on their own intimacy and sexuality?

# METHOD

## Design

This study employed an exploratory design consisting of one-off semi-structured interviews with women who had been diagnosed and treated for breast cancer and their partners. The aim was to explore how they made sense of their bodies and sexual relationships following treatment for breast cancer. The qualitative method of Interpretative Phenomenological Analysis (IPA; Smith, 2003) was chosen as the most appropriate method of analysis. Within IPA there is belief that knowledge and understanding are embedded in individuals' everyday worlds and the aim of the researcher is to explore and describe as accurately as possible the social and psychological phenomena, refraining from any pre-given theory, deduction or assumption (Groenewald, 2004; Smith & Osborn, 2003; Smith, Flowers & Larkin, 2009). Within this approach there is a focus on subjective truth or reality and not whether the individuals accounts are 'true' or 'false', this is because the search for meaning in their accounts surpasses any objective truth (Reid, Flowers & Larkin, 2005).

IPA researchers are engaged in a 'double hermeneutic' in that they interpret the participants' accounts through their own conceptual and perceptual lens (Smith et al., 2009). Therefore, IPA researchers are encouraged to reflect upon the values, experiences, interests, preconceptions and assumptions that they bring to the research process. Such reflexivity helps to ensure the accessibility and clarity of IPA (Brocki & Wearden, 2006). A reflexive diary was kept throughout the interviews and also functioned as a credibility checking method during the analysis process (Appendix 7).

### Setting

Nurse Specialists in the Cancer Service at Good Hope Hospital in Sutton Coldfield identified and initially recruited women and their partners who had undergone surgical treatment for breast cancer at that hospital. The Nurse Specialists and the Clinical Psychologist at this hospital had developed the initial idea for this research project as a result of their clinical work and gaps in the research literature

### Ethics

Ethical approval for this study was granted by the West Midlands Research Ethics Committee (May 2011; Appendix 8). The Heart of England NHS Foundation Trust Research and Development department approved the study to be carried out within the cancer service at Good Hope Hospital, Sutton Coldfield (July 2011; Appendix 9). This research was carried out in accordance with the British Psychological Society Good Practice Guidelines for the Conduct of research within the NHS (Cooper, Turpin, Bucks & Kent, 2004).

### Sampling

This study researches couples where the female participant had undergone surgery and treatment for breast cancer. The women in the sample had all undergone a mastectomy with immediate reconstruction, either using their own tissue or synthetic implants. The participants in this study represent a homogenous, purposive sample in line with IPA methodology, selected because they share the experience of a particular situation, event or condition (Smith & Osborne, 2003, Willig, 2008). Homogeneity is not claimed in terms of sample characteristics, but rather in terms of participants' shared experience, which is important for an IPA study. Participants were approached by clinic breast care nurses within the cancer clinic at a regional hospital and asked for participation in the research. A letter, details of the study and contact details for the researcher were given to each interested participant (Appendix 10 & 11). The participants were recruited based on the inclusion criteria summaried in Figure 1 below. No individuals declined to take part or were excluded from the study for not meeting the inclusion criteria. All individuals were previously known to the breast care nurses.

**Figure 1. Inclusion Criteria**

**Inclusion Criteria**

- Heterosexual couples between the ages or 18 and 65 where the woman has been diagnosed with breast cancer and has undergone a mastectomy with reconstruction
- Couples who are currently married or cohabiting
- Currently in remission
- Participants who are 6 months post treatment
- Participants who were not currently receiving psychological therapy from the psychology team
- Individuals who are competent to give informed consent
- Individuals with a clear and demonstrated understanding of spoken English

Contact was made with the interested individuals by the researcher prior to the interviews taking part and informed consent was gained (Appendix 12), any questions the participants had were answered at that time. The participants in this paper represent the first four couples who agreed to participate. The sample size (n=8) in this study is within the average range for an IPA study. Within IPA research there is an emphasis on the detailed analysis of each case followed by comparison across cases. In this study cases can be compared at the individual and couple level.

## Sample characteristics

Names of participants have been changed to protect confidentiality. The four couples were: Nina and Harvey, Jennifer and Steve, Sadie and Alastair, and Jemma and Mitch. Within the four couples their ages ranged from 37 years to 55 years old. Two couples described themselves as White British, one couple as Asian British and one couple as African British. The women had all been diagnosed with breast cancer, of whom 3 had been diagnosed with invasive breast cancer (lobular, ductal, or a mix of both) and 1 had an early form of breast cancer (ductal carcinoma in situ, DCIS). All women had undergone a mastectomy with immediate reconstruction on one breast, of these 3 had reconstructions using their own tissue and 1 using implants plus own tissue. All women were between 7 months and 3 years post-surgery. The couples had been in their relationships from between 10 years and 26 years, all had between 2 and 4 children ranging in age from 2 years to 24 years.

## Data Collection

Participants were individually interviewed using a semi-structured interview format. The schedule was developed in accordance with the conventions of semi-structured interviewing (Smith, 1995; Willig, 2008). The interview schedule was devised by the lead researcher and reviewed by two colleagues and amended accordingly. The interview schedule consisted of some broad questions relating to the time of cancer diagnosis and their experiences of treatment, surgery and body image. This helped to set the scene and enabled participants to tell their story from start to finish. The questions were broadly similar for the male or female within each couple (see Appendix 13). Each member of the couple was interviewed individually in an attempt to ensure maximum comfort in talking openly about their experiences, thoughts and feelings. One couple was interviewed per day to enable the researcher to fully focus and reflect on the day's interviews. Interviews took place within the hospital in a sound-proofed room and were undertaken at a time convenient to the participants. The interviews lasted between 30 minutes and two hours each. Information packs were provided following the interview with information regarding services available for further support for the couples.

The interviews were digitally audio-recorded and transcribed verbatim, these transcripts constituted the raw data for the study. All names were replaced with pseudonyms to protect confidentiality. The accuracy of the transcripts was checked and details corrected as needed. Following the initial analysis of the interview data participants were asked if they would like to review the quotes that they gave. This gave them the opportunity to decide if they were happy for their quotes to be used in the research report.

## Analysis

The data were analyzed using IPA. The analysis followed a five-stage process described in detail in Smith et al. (2009). The first stage of analysis involved listening to the interviews whilst reading the transcripts, immersing myself in the data to ensure the each interview participant became the focus of the analysis documenting any thoughts, feelings, assumptions, questions and concerns that came to mind whilst reading the text. This was then placed to one side and an attempt was made to ‘bracket off’ personal thoughts, values and existing theoretical assertions. The second stage involved systematic descriptive, linguistic and conceptual coding of the data line-by-line; these were noted on the left-hand side of the page. Descriptive coding resulted in noting the key words, phrases or explanations that the participant used, to build an understanding of the ‘things that mattered’ to the participant during the breast cancer process (Smith et al, 2009). Linguistic coding was concerned with noting how language was used by the participant to reflect the content and meaning of their experiences, for example use of laughter, pauses, analogy or repetition. Finally, conceptual coding involved a more interpretive approach and moved away from focusing on the smaller units of data to understanding how these data might fit into a broader concept that might be common across specific instances within an individual transcript. Further readings followed to ensure full analysis and capture of the participants’ complete experience. In stage-three these initial notations were translated into emergent themes at one higher level of abstraction and noted in the right-hand margin (Appendix 14). In the fourth stage the themes were reviewed on post-it notes clustered together to identify connections made between the themes whilst exploring the convergence and divergence of themes for each participant (Appendix 15). The fifth stage resulted in patterns of themes being identified across individuals, couples and across gender. These themes were then drawn together to create super-ordinate themes. A small number of themes that were not relevant were excluded. To ensure credibility and reflexivity, at the end of each interview and when listening to the interviews at the initial stages of analysis, my thoughts, feelings and overall impressions of the process were noted in the reflexive journal. Regular discussions with academic and clinical supervisors also took place and I accessed peer support through an IPA trainee group and I utilised an international IPA discussion group.

## Reflexive statement

My identity as a female, with my own experiences of body image and close experiences with cancer have likely influenced my choice of research, the conduct of the inquiry, and the interpretations of the data in both conscious and unconscious ways. I have experienced family members and friends who have been diagnosed and treated for cancer. These experiences motivated me to conduct this project because I wanted to develop a close understanding of how this treatment process affects individuals, and particularly within intimate relationships. However, rather than viewing the beliefs and experiences of the researcher as biases that need to be eliminated, IPA adopts the stance that these are inevitable agents in the process of making sense of the experience of others (Smith et al. 1999).

Knowing from personal experience that many people who experience cancer are very gracious in their desire to 'give a little back', I was mindful of being able to "give voice" to couples' experiences and wanted to make participation in the research a positive and empowering experience for the couples involved.

## RESULTS

Three main super-ordinate themes emerged from the in-depth analysis: *Cancer as a central threat, the body as a central concern and centrality of communication.* Within these super-ordinate themes there were ten emerging sub-ordinate themes, which are presented below in Table 2. The final themes were chosen for not only their prevalence but also their richness and the importance placed on them by participants. Divergence and convergence within case level themes are key features of the IPA process; therefore whilst most sub-ordinate themes represented all participants' accounts, not all did (Eatough & Smith, 2008).

**Table 2. Super-ordinate and sub-ordinate themes Identified**

| Super-ordinate | Sub-ordinate |
|---|---|
| ***1. Cancer as central threat*** | |
| **Across couples** | • Being together<br>• Men being practical |
| ***2. The body as a central concern*** | |
| **Women** | • Threat of monstrosity, threat to normality<br>• Promise of repair<br>• Threat to physical intimacy and sexuality |
| **Men** | • Relief at survival / recovery<br>• The body changes |
| ***3. Centrality of communication*** | |
| **Women** | • Avoidance – not talking about It |
| **Men** | • Reading the signs/Treading on eggshells |
| **Across couples** | • Building communication |

Each individual's experiences were multifaceted and variable, therefore whilst each theme is presented independently of each other there is considerable overlap between themes. Each theme also fits within a process for each couple that was dynamic and changeable, with a focus changing from cancer to the female body, then moving again to focus on building relationships.

### Theme 1: Cancer as a central threat

In this paper the analysis will focus primarily upon couple's experiences of breast cancer treatment and the resulting impact on sexuality and body image. However, it is important to begin by placing these experiences in the context of receiving a diagnosis of breast cancer. The beginning of the interviews involved the participants telling their stories of when they were first diagnosed, reactions to diagnosis and the discussions they had with the medical staff around the treatment available. The theme of 'cancer as a central threat' explores how the couples describe and understand their journey from diagnosis to breast surgery. From each participant's understanding of the early days of being diagnosed with cancer there was a sense of "being together" and having a shared understanding of cancer as a central threat. Whilst men wanted to be part of the decision-making process they were mindful of putting their wives' needs or preferences first and supporting whatever decision was made. During the time of diagnosis and considering treatment men saw themselves, and were described by their wives, in practical terms. Men took the role of gatekeeping, looking after their wives and also of attempting to maintain 'normality' and portraying a united front for other members of the family, such as children, and people outside of the family.

#### a. Being together

All four couples described the process of being diagnosed and having to make decisions about surgery. This process was described in the context of the couple, with information being received and digested together. This ‘togetherness’ was seen to have a protective function for either the partner or the wider family. In the following extract Sadie describes how onlookers noticed Sadie’s body language towards her husband in social situations, this illustrates a ‘togetherness’ and wanting to protect her partner around the time of diagnosis and the initial ‘shock’:

> *“It was, when I was first [diagnosed], we kept it quiet because it was just before Christmas, it was the middle of December, we wanted to get our own heads around it, didn’t want to tell anybody until after Christmas and we knew what was happening. Erm, and, it was afterwards it was people….the couples that we probably see…you were so much more…I don’t know…together – in as much as you know like we’d go into the group and we kind of just, you’d be chatting and different people whereas we kind of stuck together. And we probably didn’t notice that about ourselves but…. afterwards, they said they’d noticed. And actually when they found, it was all they…but one couple said we actually thought there was something wrong with Alastair cos you were being incredibly protective of Alastair…”* **(Sadie)**

This was something Sadie reflected on at the time and interpreted as due to her ‘mothering instinct’ and desire to protect those she loved from distress. On occasions this togetherness appeared to evoke feelings of guilt. Some of the couple's accounts suggested a need to protect their partner from the enormity of being diagnosed with cancer and the distress this knowledge might cause. It appeared that for both the woman diagnosed with cancer and her partner, the diagnosis and decisions to be made for treatment presented as quite overwhelming. This resulted in initial indecision and lengthy discussions within the partnership about the way forward. An example of this in the following extract is Alastair's description of decision-making, suggesting a shared turn-taking process within Sadie and Alastair's decision-making about surgery:

> *I think we just batted…back and forth over, you know several weeks. Erm, it was…well I think the lymph operation helped in a sense because that then sort of suggested that we were in a better place than have it. I mean if it have gone…if it had barely been positive, I don't think that would have been an option, so, erm, in a way that helped in the decision making process and we kept batting it back and forth and…you know I was probably thinking at the end of the day it's up to you, but you know, I can't make the decision for you, but, I think I kept going back to the fact that the consultant was suggesting that decision."* **(Alastair)**

Whilst Alastair and the other husbands were active and involved in the decision-making process, all couples had a primary focus on "banishing the cancer". Jennifer wanted to 'obliterate' the cancer, particularly as this was the return of a breast cancer she had been clear from for five years. She asked the surgery staff to *"Get rid of it, can you just get rid of it?"* Sadie similarly wanted radical action and appeared to be reluctant to consider surgery other than a mastectomy "*Erm, so I guess, at the…feelings erm, just wanted rid of it, erm, so at the time I wasn't even thinking about whether I'd have no breast at all it was just get rid of bloody cancer"*. Nina was also adamant that *"this thing needed to come out"*, despite the conflict between aesthetics and preserving life. Nina's husband Harvey reiterated that the primary thought for them was to deal with the cancer:

> *Uh, my primary thought, um, was about get rid of the cancer, you know, come what may. I wasn't sort of bothered as to whether she, um, had, um, you know, the mastectomy, as long as her overall health was sort of fine.*

> *Um, so in I, I suppose throughout the sort of stages it was about, um, what's going to be best for her as part of her sort of treatment. And it was, you know, um, sort of reassurances when she had, um, uh, the lumpectomy, they also took glands and this was clear – so there's all those processes of, you know, hopes and then hopes being dashed, and, um…***(Harvey)**

Harvey's consideration of 'what was best' for his wife was a common theme amongst the partners. This understanding and acceptance from partners was evident in their understanding of their wives' reasons for wanting a mastectomy with reconstruction, even if they placed less importance themselves on whether the breast was reconstructed or not, as illustrated in the extract below. Alastair is recognising Sadie's desire to have a breast that fits with her belief about her body:

> *"From Sadie's point of view and perhaps from the outside world [immediate reconstruction is] more aesthetically pleasing, erm, and also, I guess she…felt it was worth doing, you know."* **(Alastair)**

Alastair demonstrates his support of Sadie's decision, whilst suggesting through his acknowledgement of the "outside world" point of view that this is not a view he shares, that he places less importance on the need for reconstruction. Supporting decisions is also demonstrated in the quote from Steve below. Whilst Steve has been involved in the decision-making process, the decision was ultimately made by Jennifer:

> *"The decision's always been down to Jennifer. Um, I've always, I've always gone along with whatever Jennifer's wanted to do. And mainly whatever she's decided I've sort, I've sort of thought... I've agreed. I think she's gone always down the right path. I've never sort of thought she's diverted off it so I think she's right with what she's done."* **(Steve)**

In this extract Steve is showing confidence and support in Jennifer's decisions, further supporting a sense of togetherness and shared goals. Inherent in the decision to undergo breast cancer surgery is an element of risk. All couples described the shared decision-making process with a wealth of information presented by the medical team. Not wanting to have more than one operation was something that three of the couples highlighted as a key consideration in the decision-making process. It was felt that an immediate reconstruction would be easier than the alternative immediate delayed or delayed reconstructions. Alastair reflected on the pragmatics of making a decision in the context of the particular time point around diagnosis. There is a sense that he voiced what the other couples also felt, *"you just have to go with the right decision at that time".* The practical nature of the husbands' thoughts and actions during diagnosis, and the decision-making process, was something that arose in all participants' accounts. This will be discussed in the next sub-ordinate theme.

### b. Men being practical

This theme captured accounts of men providing practical support and also their thoughts about coping with and moving forward in the context of their wives' illnesses. It is in the context of the cancer being perceived as a central threat that men were the gatekeepers, protecting their wives and families and attempting to maintain normality. This was not always an easy process and often men encountered difficulties or gave accounts that indicated a struggle. In the following extract Harvey illustrates his pragmatic approach to processing the enormity of Nina's diagnosis when telling their daughter the news:

> *"I suppose I sort of coped with it from, um, stage by stage, um: always hoping for the best but having a bit of apprehension as to where things might go. I suppose during this, the times, the hardest bits were, um, because it was me, uh, the one who had to tell the kids and, um, at that time I, um, this daughter she was on foreign travel in China and Vietnam and we had to sort of make out that, you know, it was only a cyst and things would be all right. And she didn't really find out until she got back and we took her to Oxford, and then she wanted to jack that in, and, you know, try to persuade her, you know, you can't sit around for a year; it's cracking on with your life…I do have… the kids ask me how I'm doing. And my bog standard sort of response is, you know, that I'm all right and we need to sort of think about the next stage."* **(Harvey)**

Harvey's experiences of fielding questions or the concern of children is an example resonant in many of the husband's accounts. It captures a sense of wanting to protect the family and attempting to 'contain the cancer' and the distress it had the potential to cause. It is no surprise, under the circumstances, that experiences following a diagnosis of cancer are described in terms of 'getting by or 'muddling through'. Practical help in the form of verbal reassurance or encouragement to attend appointments were roles that the husband provided. Sadie described how her and Alastair approached the subject with their children "*we kind of, made a pact that as far as possible we would keep things as normal for them, cos what I didn't want them doing was getting upset or you know, stressed about it"*. Jemma talks of how her husband, Mitch helped out with the children when she couldn't and how he *"helped me with housework".* For Jennifer, whose cancer had returned, Steve provided much needed reassurance and practical help in attending appointments in the early days around the time of diagnosis:

> *“”I think it's just the anxiety of “”I've got to go for this””, you know. I mean she was on about not going and I said, “"No, no you've got to go"” like. “"I don't want to..."” she don't want to go but I always make sure she goes. She would go but it's like an initial "”No I don't want to know”" you know.”* **(Steve)**

This account illustrates that even in a difficult situation, where Steve is potentially encouraging Jennifer to go to an appointment that will cause distress, Steve is considering Jennifer’s needs and wanting to be there to protect her by attending appointments together. Similarly, a powerful example of protection from the outside world, but also the ‘central threat of cancer’ was recalled by Harvey. He perceives that Nina is struggling to talk about her diagnosis and the decision making process and between them they ‘take action’:

> *“Sometimes I felt that she didn’t want to sort of talk about it; but other times, um, she, uh, um, when she was probably a bit more sort of relaxed about it and not so anxious and not so irritable about people asking her questions – because one of the things I think made her sort of fed up was having to constantly repeat and repeat what’s going on. And we just had to get to a stage of just banning people from coming to the house; and say if anybody wanted to talk about it they spoke to me about it, and not just getting her to repeat it and relive it over and over again.”* **_(Harvey_)**

This powerful example captures the traumatising potential of cancer for Nina, and indeed all of the women in this study. It also captures Harvey’s sense of wanting to protect Nina once again. At times, there was a sense in the majority of the couple’s accounts, that attempting to maintain ‘normality’ was extremely difficult, particularly in the context of worrying thoughts. Prior to surgery, there were worries about the enormity of the operation:

> *"The fear is that you're going…you know, going under the anaesthetic, going in for an operation of that length that you might not come out the other end, but er, those are sort or irrational fears you have at the time, and er, that was something that was worrying me particularly about Sadie."* **(Alastair)**

Alastair's account is representative of many of the participants' realisations of the enormity of not only the cancer but the treatment to remove the cancer. During the time of diagnosis, and the difficult period when decisions were made about what type of treatment and surgery that would follow, there is a centrality of a united fight against cancer. The couples negotiate their way through this process whilst having a shared goal of eradicating the cancer and becoming well again. However, this appears to be only the start of a dynamic process of the couples finding they 'come together' on shared goals or 'pull apart' with each having a different focus during different stages of the cancer process. In the next section, the body becomes a central concern, with the couple's accounts diverging and 'pulling apart'.

### Theme 2: The body becomes a central concern

This theme encompasses a divergence in the accounts of the husbands and wives in this study. Whilst a central focus during diagnosis and decision making was around struggling with cancer, following surgery the focus for the couples became about struggling with physical recovery. What is most powerful in these narratives is that the women's accounts clustered in themes around surgery being a 'threat of monstrosity and a threat to normality', a perception of a 'promise of repair not met' by the surgeon and a personal 'fight for control over the body'. However the men's accounts focused on a ‘relief at survival’ following surgery and a positive acceptance that ‘the body changes’ either as a result of time passing with age or through life events, including cancer. Each of these themes will be explored in turn in the following section.

a. Threat of monstrosity and a threat to normality

Women’s perceptions or feelings towards their bodies were the predominant experiential features of the women's accounts. These perceptions were as a direct result of the breast cancer treatment they underwent. The three major issues for the women were either; complications during recovery, disappointment with the end result of the breast surgery, or distress at the amount of weight gained as a result of chemotherapy and medication. These issues all tapped into the women’s sense of the body as a ‘threat of monstrosity and threat to normality’. These threats were described by all of the women, either a perception prior to surgery or worries and concerns following surgery. Prior to surgery Nina described a dilemma of wanting a ‘normal’ breast but also of the desire for reconstruction following the effects of having had two lumpectomies prior to the reconstruction, however she was concerned about the finished results:

> *“And there's this sort of in your head and this option that when you have a reconstruction you're just going to have a normal looking breast. And so it's so, it's so not like that because he gave me a set of websites to come back and look at. And breast reconstructions yeah they give you, they give you a mass there so that you're not flat chested on the one side, but, but really they look nothing like what I wanted and was used to looking like. So it was, it was very, very distressing”* **(Nina)**

Nina's account is representative of the feelings experienced by the women. The results of surgery were also often difficult for the women to accept, feelings of shock where experienced, partly due to the enormity of the surgery itself. However, the men's experiences were different; these accounts will be discussed later. Women described a sense of trepidation about the surgery and the results. Jemma felt the loss of her ‘normal’ breast and an alienation from her reconstructed breast, *“I will not be comfortable because even now, I’m still not, comfortable the way I am. A significant part of my body is not complete”.* There was also a sense of women externalising their breasts by talking about them as separate from the rest of their bodies. Sadie, Nina, Jemma and Jennifer all described their initial reactions to their post-surgery breasts. In the following extract, Jennifer describes her feelings having surgery and wanting to feel and look ‘normal’:

> *“My only thing was I didn’t want it got rid of but not have the reconstruction at the same time. I couldn’t live with the thought of coming round to nothing. I said that at that point would destroy me; I couldn’t do it. It was: you’ve got to get rid of it; you’ve got to replace it; I want to wake up and feel like it’s there as such. Um, so… I think it was the thought of feeling whole. But it was also I think the biggest thing was my, well our two daughters: I didn’t want them to look at me any different; I didn’t want to be looked at alien; I didn’t want to be looked at in a different way.*

Jennifer’s account is representative of the other women’s concerns about their children’s perceptions of their mother. Some of the women were less concerned about their children but were nevertheless concerned about outside perceptions. Sadie described how she felt at ease with her breasts prior to breast cancer, despite changes due to age and childbirth. However, she used to go topless when at the beach, but that this isn’t something she would want to do now, thus threatening her sense of ‘normality’:

> *Erm, they were just getting older, um, truthfully, haha…yeah, erm, I don’t know yeah, gravity…age was taking over, they were…weren’t too bad erm, I was confident, I mean I’ve sunbathed topless cos it’s like well who cares no one’s looking at my boobs anyway…so what the hell. Erm, so, and I think that’s funny now, co…covering up is like another…I don’t…I mean certainly with the scarring at the moment, erm, I’ve obviously kept it covered and stuff and with being away, which is…which is very unusual for me, for a number of years.* **(Sadie)**

Similarly, Jemma described ‘hiding’ in her dressing gown around the house for fear of her small children asking questions:

> *“I think, it’s like your hiding…hiding yourself. You know like kids, my kids they come into my room if I’m dressing or they pick my robe, I’d probably hide, I don’t want the kids to see me not complete and be scared”* **(Jemma)**

This was something that was unusual for her and caused Jemma great distress. For all the women there was a sense that some elements of the surgery were successful but some parts of the process were a huge disappointment, which left not only physical, but psychological scars. Most women described feeling that the surgeons had offered a restoration of normality in having an immediate breast reconstruction, but for the women here there was a sense of ‘a promise of repair not met’. This theme is discussed in the next section.

### b. Promise of repair not met

For all four women there was a strong presence of the surgeons in each of their accounts; this also followed a dynamic process, from diagnosis and decision making to surgery and recovery. There was a sense that during the decision making process the women were offered ‘repair’. The women describe being told that an immediate reconstruction would give them the opportunity to remove the cancer whilst giving a new aesthetically enhanced breast and stomach. In this way, Nina’s account below demonstrates the ambivalent relationship all the women had with the surgeons:

> *“They get so excited about ((laughing)), their work and what a breast looks like and how fantastic they can make you look and you'll be pleased with it, and it won't be as droopy as your other one. And, you know, what... it, it almost makes it that I think they're trained to make you think they're giving you a treat after all you've been through”* **(Nina)**

The perceived artistry of the surgeon resonates throughout the women’s accounts. The fragile relationship between artist and breast owner was often subject to rupture. Nina also gave a potent account of how powerless and vulnerable she felt immediately following surgery:

> *“I came out of theatre at night and was obviously out of it all night, the first thing in the morning this plastic surgeon came in and said, "Do you want to have a look?" I thought already, you know, it'll be horrible and they'll be blood everywhere and it'll be sore and it'll be really tender. And I said, "No I'm not in a hurry" and he just took the strip off my breast to show me and said, "Oh that's lovely I'm really pleased" and I just wanted to cry.”* **(Nina)**

Nina’s words highlight the fragile position these women were in during the days following surgery and the differing expectations of surgeon and patient. Sadie described her expectations for surgery and the prospect of positive changes in her body following treatment; however these were not always met:

> *"then of course I had the…what effectively is a tummy tuck operation and you think…wow, I'm gonna get the rest of the body to match that now…I'm…I'm gonna…I'm gonna do this thing now. Had the chemo and piled on loads of weight, so that was a bit…a bit shitty…hahah…"* **(Sadie)**

Sadie became particularly despondent with repeated efforts to lose weight following treatment, something that is hindered by medication to prevent the cancer recurring. This sense of trying to maintain control over treatment and the body was experienced by all the women. Jemma reflected on how she may have done it differently had she known she would need to undergo radiotherapy after her reconstruction, which ultimately may have created issues with her implant:

> *"I would have said ok, maybe…maybe with, undergone the reconstruction a little bit later, I'll go for this. But no…no…nobody told me, no idea of what is going on. So it's really hard and you don't know what is going on, you are just fumbling with what…they are telling you"* **(Jemma)**

This sense of bewilderment about the events surrounding surgery was common. Jennifer described finding out that the surgeon had created a new belly button, she found this devastating and a shock:

> *I didn't know. As far as I was concerned I was having mastectomy, reconstruction, stomach muscles; that was all I was told; that was all I was led to believe. I was not told, "Look at this website, look at this piece of paper, cosmetically this is what you're going to have, you're going to have a new belly button". It was as if I'd had more done, which I did, to what I'd expected. And at that point it was I had to readjust to it all in my head. And it*

> *was quite strange to have to readjust to so much of the body area being touched and being… it wasn't the fact – I can't explain it – it wasn't the fact that they'd invaded the body as such – that's the only thing… ((laughs)) that's the only way I can think of it – it was the fact they'd done what they did but he, he assumed I knew what he was going to do. I knew about the stomach, I knew about the mastectomy; didn't know about anything else"* **(Jennifer)**

Jennifer talks of extreme vulnerability. Having to assimilate new information about changes to her body was particularly difficult, especially when she felt she was powerless in the decision making process. These accounts highlight the difficult road to accepting the body immediately following surgery. This bumpy road continues for the women when they attempt to resume the sexual side to their relationships. This will be discussed in the following sub-ordinate theme.

### c. Threat to physical intimacy and sexuality

For the women there appeared to be barriers to physical intimacy due to breast cancer surgery and treatment. Whilst amongst the women there was differing acceptance in terms of their physical appearance, a central theme for all women related to their ability to feel at ease physically with their partners. Sadie, Nina, Jemma, and Jennifer all talked of wanting to cover up in front of their partners and not feeling as confident being naked in front of them. Adjuvant treatment such as chemotherapy, biological therapies and hormonal therapies were also indicated by women to affect their feelings around physical intimacy. The first time having sex following surgery was recalled as a difficult time; feelings of fear and discomfort were common. In this way, the extract below highlights Jemma's fear about having sex for the first time. She was worried about her husband's perceptions of her body and how she herself felt 'incomplete':

> *"After surgery. I was…it like…I was not really in the mood, but, I thought, I'll make the mood, I said to him, I don't want him to be angry, but it's like, I'm not complete, well you have…probably seen something else…but this is not what you saw before. So he told me that he's not really bothered that I'm ok the way I am, as long as I'm…he's with me and ok. But I am not complete I don't want him to see me like this, and sometimes if I just want to, I tell him, don't you see how different it is, it is a big difference with this"* **(Jemma)**

Jemma's account above also illustrates her husband's reassurance that he is accepting of her body following treatment. This is common within all four couples and is a central theme across both the men and women's accounts. What particularly stands out are the couples' polarised positions on the women's bodies. The women are disbelieving that their husbands could find them attractive, whereas the men assert that they do indeed find their wives attractive, just as much as before breast cancer was diagnosed. All four women expressed initial disbelief in their husband's compliments or reassurance about their bodies and felt that their own feelings about their bodies directly contributed to difficulties resuming a sexual relationship following surgery. Sadie highlights this when talking about the first time she and Alastair had sex following surgery:

> *"I struggled to do…struggled to think about anything other than what Alastair was seeing. So for me it wasn't possible to relax, enjoy, e...a...it. I was just conscious of what, you know, what was there…the fact that it was different. Although not different in some ways, but yes, it was…it was different, erm, so, it was just…yeah it was…it was actually quite hard because you still*

> *perceive…or you…you still have this perception of your body and you know, I've still, you know, the scars aren't going to go away, it's a case of, they are just part of who and what you are now going forward.  Erm, but equally it's, you know, your…that certainly the first few times all you're thinking is, oh my God,…this can't be nice for Alastair anymore, I'm kind of thinking about that, thinking oh God and just couldn't…just couldn't get with it at all"* **(Sadie)**

Sadie describes a fear of intimacy and a fear of rejection from her husband, which is evident in all the women's accounts. The women talk about how different they feel and how difficult it is to see themselves as sexual beings and to accept the differences in their bodies. For some of the women these issues predated their diagnosis of breast cancer. It appears that being diagnosed and treated for breast cancer brings to the forefront, the women's past and present feelings about their bodies, particularly when it comes to sexual intimacy. In the next section the husbands' accounts will be discussed.

### d. Relief at survival

All four husbands spoke of their priorities and relief that their wives had survived surgery. The men grappled with coming to terms with the enormity of surgery and of wanting to offer support and help to their wives. Steve talked about seeing Jennifer immediately after surgery and the impact this had on him:

> *"She was in intensive care; the operation was like over nine hours I couldn't believe it like, you know, she was in a right state. It upset me that did seeing, seeing how she was like, you know, you think bloody hell, you know, such a massive operation it was it was huge. ... because it was like, you know, it's just like as if someone's been hit by a car or you've been in a road accident*

> *or I don't know you fell off a building that's how she looked. And you just look really dodgy like, you know, you go, is she going to pull through like, you know, it just upset me like, you know…..so then my total thing is that, um, Jennifer survived, um, that obviously the children have still got a mother and that was the main... and that, you know, she was recovering, which she was. You know, and initial reaction is that she's survived, you know, the operation i.e., the cancer and it's, it's removed…"* **(Steve)**

Steve's account above is particularly powerful. The description of Jennifer looking like she had been in a car accident or fallen from a building evokes a strong image and conveys the felt enormity of the situation and the assault on Jennifer's body. Similarly, the reconstructive side of the surgery was not a priority for Harvey, just his wife's physical and emotional wellbeing:

> *"I probably didn't sort of think about the shape of her, her body etc. My first and foremost concern in the front of my mind would have been about her emotional feelings and, you know, how she's coping with it and, you know, so on"* **(Harvey)**

Steve and Harvey also talk of recovery and later, of helping in practical ways. This practical aspect overlaps with the previous theme of 'men being practical'. Mitch and Alastair talked explicitly about helping their wives with medical care, this highlights again the dynamic nature of the breast cancer journey for these couples in that caring for their wives brings the couples closer, and with that a sense of togetherness:

> *"Sometimes I used to help her to…to dress it you know cos at the time the district nurses were…were not coming any more to help her to do the dressing, she has to do the dressing herself and she was finding it very hard*

> *to do, so I have to help her to…to do the dressing and things like that you know"* **(Mitch)**

There was a sense of muddling through these early days together and tentatively entering uncharted waters. Whilst the women struggled to come to terms with either their new breast or the changes elsewhere in their bodies, the men were pleased with the results of surgery and accepting of the changes that had taken place physically. This is illustrated in the theme "the body changes" below.

e. The body changes

The overwhelming theme within the husband's accounts related to their reactions to their wives' bodies post-surgery. All men expressed satisfaction with the reconstructive surgery, although they were mindful of their wives dissatisfaction and their feelings towards their bodies. Alastair describes, in the extract below, his expectations around surgery and his way of coping with uncertainty:

> *I think I was expecting it to be much worse than it was…the scarring and everything was far better than I probably anticipated but then I think perhaps part of that is, you fear the worst, and therefore if the end results better then that's…that's a good result [.….] I think she's looking great now, erm. she's…sure I suppose she'll say she's put on a fair bit of weight, she was a fair bit slimmer before erm, and I think she's probably more concerned about that than I am but, er, you know, that's perhaps understandable"* **(Alastair)**

What is different here from the women's accounts is how expectations for the men were developed and subsequently met, whereas the women's expectations were not satisfactorily met. Alastair's acceptance of Sadie's body post-surgery is reiterated through the interview, as it is in all the husband’s accounts. Steve, Mitch, Harvey and Alastair all enjoyed looking at their wives from an aesthetic perspective:

> *“When she used to get out of the shower and things and, um, get changed in front of me. And, um, uh, and I used to enjoy looking at her body in, uh, you know, bras and pants and, um and even now when she does that […] I still enjoy doing that. Um, and I’m not doing it from just to say, “Oh look, does it look any different” or anything; I’m just, you know, I’m just enjoying the whole, you know, visualisation of her and her body. Um, and I do compliment her on it, sort of saying, “You’re looking particularly… this morning. I don’t know whether she feels I genuinely mean that or I’m just constantly sort of saying that as a reassurance; but I do genuinely mean it. So, so to me I don’t think that I’ve changed my sort of view as to how, how good she looks, you know, naked or otherwise”* **(Harvey)**

Harvey was uncertain whether Nina believed his compliments, whilst he took obvious pleasure in his wife's physical form; he was unsure whether his wife understood his appreciation of her body. There is also an acknowledgement in the husbands’ accounts that bodies change with time, for both the husbands and the wives, and that this is to be expected. Below Steve talks about Jennifer and how he continues to find her attractive despite changes through age, childbirth or cancer treatment:

> *“Um, yeah well I mean I've known Jennifer for about 25 years like and I've always, you know, and she's always had a nice body like, you know. Even though she has... she's put weight on I've never, you know... it's never bothered me, not at all… obviously because we've known each other for so*

> *long she's, um, I've just, not just her body, her, everything about her really, you know... and I still do, you know"* **(Steve)**

Like other husbands, Steve is demonstrating that intimacy has multiple levels, of which physical attraction is just one. In the husbands' accounts, there was talk of needing to consider their wives' feelings during sex and whether they were experiencing pain or discomfort. There is also an acknowledgement that the process took time and consideration needed to be given to taking things slowly. Noticeable, when interviewing the couples, was the centrality of communication. Each couple talked about thoughts and conversations they had with themselves, but had not yet had fully with their partners. This will be discussed in the final theme below.

### Theme 3: Centrality of communication

Throughout the couples' narrative accounts there were references to the couple as a unit and how they negotiated their way through body image and sexuality concerns following breast cancer treatment. However, there were times when this was not directly communicated. The women's accounts suggested a pattern of 'avoidance'; consciously or unconsciously, not wanting to directly discuss concerns at some points. The men described attempting to read the non-verbal cues that their partners gave in situations that involved affection or sexual intimacy, which led to them 'treading on eggshells'. However, the wives and husbands came together in their accounts in terms of thinking about the future and the need to communicate more clearly in order to build a relationship with their bodies and with each other.

a. Avoidance

Within this theme, Gemma, Sadie, Nina and Jennifer gave accounts of wanting or feeling the need to communicate with their partners about how they feel about their bodies and sexual relationships. In the extract below, Sadie reflects on not discussing issues she felt were present in her sexual relationship and the fear these discussions raise:

> *"Cos we just didn't talk about it, when actually we probably should have done. Erm, because what you end up doing is thinking…me thinking that he doesn't find me attractive any more…and then…him probably thinking the same, in hindsight. I haven't discussed it, probably because I don't want him to say that he does find me unattractive, or that you know, he doesn't love me enough anymore…I don't…and I'm sure he does, but…but then…I'm sure…I'm sure…I mean I'm sure…I'm sure…I bloody hope he does"* **(Sadie)**

Sadie illustrates how when she reflected on her satisfaction with her sexual relationship she found that she avoided talking about it. She was fearful of Alastair's response and the rejection she perceived this might lead to, that she would discover that he doesn't find her attractive anymore, for Sadie this also equated to Alastair not loving her anymore. Jennifer also discusses how she finds it difficult to talk about sex, however for Jennifer it is because this means talking about her body and this is something she finds particularly painful:

> *"To discuss something as intimate as sex I struggle with that because it's talking about me physically and I can't do that. But I cannot do the intimate thing, going the next level to discuss it. I can talk about the before, I can talk about how I feel and why I don't want to [have sex]; but I can't go through that next level of intimacy. I can, I can occasionally go up to him and say,*

> *"Can I have a hug?" but if he tries to go any further I can't – I'll just go and see what [our daughter's] doing; I've just got to go and do this, do that. There's always an excuse for not doing it, because I can't go to that intimate level because how I feel about myself"* **(Jennifer)**

Whilst on some occasions the women could be honest about their feelings, there were times when they consciously didn't feel comfortable doing so or used avoidant coping strategies to circumvent a situation. For some of the women there was a sense that they shouldn't have to tell their partner what they were thinking, feeling or expecting - that the partner should know. For Nina, she believed that her reconstructed breast *"feels odd to me so it must feel odd to him"*, when asked if she had discussed this with Harvey, she said *"yeah, I've just told him I don't like it"*. Nina's possible avoidance of asking Harvey what his thoughts were could suggest a fear that Harvey would confirm her beliefs about her breast.

b. Treading on eggshells

When talking about their experiences of body image and sexuality, Mitch, Harvey, Alastair and Steve described being mindful of their wives' feelings and trying to read non-verbal cues. On occasions this led to being particularly tentative and a sense of "treading on eggshells" when trying to interact with their wives. In the extract below, Harvey describes the stresses the couple have been under and how difficult that can be when wanting to express his own emotions:

> "*In the last, um, two years, uh, in terms of, you know, work, Nina's health, um, uh, have been quite challenging I must say, I suppose on both of us. And, um, uh, when I've felt like having a bit of a sort of breakdown it's almost like you're not allowed to have one, you know, because you're supposed to be the one*

> *that holds all the shit together. Um, and, uh, you do have your moments, you're talking heads conversation in the mirror about, you know: okay, how do I get through this next bit, how do I get through, uh, the next day without actually upsetting the other person or being more sensitive to what they have to say, or staying out of the way, treading on eggshells or what have you"* ***(Harvey)***

Harvey illustrates a conflict some of the men had in prioritising their own needs. There was a sense that because they were the man and the 'well partner' there was a societal or a self-imposed expectation that they must '*hold the shit together'* and be stoic in the face of emotional distress. Mitch described being able to read Jemma's non-verbal cues during sex, in the extract below he demonstrates a confidence in this understanding of his wife during intimate moments:

> *"Yeah um, we…we never talked about…talked about it at all you know. Were we like that, we just, touching each other you know, so little bit of it you know. it is something that er, I know she…she enjoys when I…when I touch her because she…she responds and things like that you know. And er, sometimes she just carry my hand to that area so then ok, she wants it on that area, things like that, you know"* **(Mitch)**

All the husbands described difficulties in trying to understand their wives, often because neither partner was openly communicating their concerns. For the men, they were concerned about upsetting their wives and causing them distress. However, with time these tensions seemed to be lifting and the husbands were able to see a clearer road ahead. Steve describes, after struggling with intimacy as a couple, noticing changes in his wife's intimacy which coincided with her stopping a hormonal therapy to prevent cancer reoccurrence:

> *"I don't like to keep being rejected constantly you see. So I usually let Jennifer take the lead and like she just grabbed me hand which I like, you know. And we've been going for walks and things and it's quite good. It's good, you know, because it brings you a bit closer together. You know before, her watching Coronation Street and I'm watching some World War II movie ((laughingly)) in the other room like, you know, so you know it's better, it's better since she's come off these tablets"* **(Steve)**

Whilst difficulties were discussed and concerns were raised in the accounts of each couple, there was an abundance of talk about hope and change. This will be discussed in the final sub-ordinate theme 'building communication'.

### c. Building communication

This sub-ordinate theme represents accounts, from both the women and the men that describe moving forward in the relationship and how communication is a part of that process of 'coming back together'. Sadie described how there needs to be a shared understanding of each partner's feelings and needs:

> *"Erm, I think from a…from a man's perspective…I …I …I think from both to know that it could be…it might be different…it might feel different and certainly for the first few times, that from the women's perspective her mind is not going to be on…fully on the making love cos her mind is gonna be thinking does…this is different, I'm different, erm, that's not gonna help in any kind of intimate situation. Erm, and so the man needs to understand that, so maybe needs to take longer, maybe…maybe there is almost this erm, you know, kind of this relationship getting back together that you… where you actually don't go for …don't go for broke the first few times. Get*

> *confidence back in the…in your body and for your partner to get confidence back as well. So for me, to get the confidence was more about knowing that you know, the confidence that I'm still loved and my partner would have still wanted to be intimate with me, but that doesn't necessarily mean that you have to…that could just be touching…that…that could just be the kissing and the hugging and the cuddles and hugs, whatever it is but…but give yourself time and…talk about it….and don't put yourself under pressure you know"* **(Sadie)**

Here Sadie recognises the need for the relationship to be built with her body, in addition to building intimacy with her husband. This sense of coming to terms with their changed bodies was common in the women's accounts, whilst some were further away from this than others. Nina highlighted the importance of taking time to get to know yourself again, and each other, and the need for adaptations physically and psychologically:

> *"Be prepared that it is going to be different, be prepared it's going to take time, um, to feel comfortable again with your partner, and be prepared to make some changes to adapt to the, the situation that you find yourself in. And also be, you know, accept the fact it's going to take time for you to deal with the effects of the entire treatment and what that does to your body and what that does to you mentally more importantly. Um, because you can only begin to feel anywhere near comfortable with your body when you've adjusted it all in your head.* **(Nina)**

Nina's quote illustrates the intertwining of body image, sexuality and psychological wellbeing, which is something the men also commented on. For the men there was a feeling that being able to talk with someone and have support for themselves would be really valuable as it was felt there was no provision for the men to seek support:

> *"But what there is, or what there isn't, is, um, while all this sort of goes on there isn't a network for blokes, you know, who can discuss these things. And I do see, when I go to the hospital with Nina, blokes with their wives, uh; but nobody has a conversation with each other"* **(Harvey)**

Talking to each person there was a sense that this was the first time they had been able to think through and reflect upon their experiences of body image and sexuality and its impact on the couple. Whilst each couple were at differing stages in their acceptance of bodily and relationship changes, each couple expressed hope for the future and a relief that the 'worst seemed to be over'.

# DISCUSSION

The aim of this study was to use a phenomenological approach to explore how women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction for breast cancer. What resulted from this study was an understanding of the dynamic process for the couple in negotiating the cancer treatment process and its effects on body image, sexual intimacy and relating within the marriage. Three main overarching themes emerged from the interviews conducted with four couples, these were ‘Cancer as a central threat’, ‘The body becomes a central concern’, and ‘Centrality of communication’.

Within the theme of the ‘body becomes a central concern’ the women in this study had strong beliefs that their partners would not find them physically or sexually attractive as a result of the changes to their bodies, as a result of surgery or weight gain due to non-surgical treatments. These perceptions were found to be inconsistent with the husbands’ accounts. This supports previous research suggesting that partners’ perceptions of their wives bodies were favourable and did not impact negatively on their desire to be intimate (Hilton et al., 2000; Wimberley et al., 2005; Carver et al., 1998).

The accounts that women gave of struggling to adapt to post-treatment sexual intimacy is consistent with previous research (Carver et al., 1998; Rowland et al., 2000; Yurek et al., 2000, Anllo, 2000; Sheppard & Ely, 2008). Some of the couples who experienced difficulties discussing sexual intimacy after breast cancer surgery identified that these difficulties had to some extent been present prior to diagnosis. This is consistent with previous research that identifies an increased risk of sexual difficulties related to breast cancer diagnosis and treatment in couples who experienced similar difficulties prior to diagnosis (Northouse, 1994).

This study also provides insights into the expectations women had about immediate breast reconstruction and post-operative effects on body image and sexual intimacy.  The theme of ‘a promise of repair not met’ illustrated the women's experiences of being given the opportunity to remove the cancer whilst also giving them a new aesthetically enhanced breast by means of cosmetic surgery. The women all talked of how they underestimated the enormity of the surgical procedure, the recovery process and the acceptability of the end results. All women felt discomfort with either the breast, the scars or weight gain associated with further treatment. These results conflict with information from a recent audit on mastectomy and breast reconstruction in hospitals in the UK where 90% of women were satisfied with the information they received pre-operatively on their surgical procedure - how it was performed, recovery time, and possible complications - (NHS Information Centre, 2011). Interestingly, in the same audit, 50% of women were not satisfied with the information they received on how much pain to expect during recovery, how long it would take “to feel normal again” and what their scars would look like and what postoperative pain to expect. Therefore this present study adds to existing research in having an understanding of the role of the plastic surgeon in setting expectations for reconstructive surgery.

Nissen, Swenson & Kind (2002) similarly found that although women felt well informed about breast surgery, they wished they had been more informed about surgery and recovery issues; following surgery they also had concerns about cosmetic outcome. More recent studies (Lee et al., 2011; Lee, Hultman & Sepucha, 2010) have reported an information deficit for both women in their knowledge of reconstruction facts and for surgeons in their knowledge of the personal preferences of women making decisions about mastectomy and reconstruction. Additionally, the issue of reporting the clinical outcomes of breast reconstruction surgery in research literature has been identified as lacking consistency and methodological rigour, suggesting that there is no standardised method for assessing and reporting complications that arise from reconstructive surgery (Potter et al., 2011). Therefore the value of this literature in informing clinical decisions, and consequently patient choices and knowledge, are potentially minimised.

This study could add to the previous research literature suggesting that women who undergo an immediate reconstruction do less well than women who undergo a mastectomy alone. Whilst in this study there was no comparison with other surgical groups, this research tentatively suggests that expectations of an immediate reconstruction play a major role in outcomes for body image and sexual intimacy. When women were offered a ‘new breast and free tummy tuck’ through cosmetic surgery, they believed that this surgery would not only restore the appearance and function of their breast but would also alleviate psychological distress associated with coming to terms with cancer. There was also a perception, gained through celebrity culture in the media, that cosmetic surgery was an easy and straightforward procedure offering highly satisfactory results. Surgeon–patient communication is critically important during a breast cancer diagnosis because the woman (and her partner) is simultaneously attempting to make sense of a potentially life-threatening illness, the loss of a breast, changes in physical appearance and decisions around unfamiliar procedures and treatment options. Further investigation needs to take place to fully understand the pre-operative process of preparing women for not only the short-term effects of surgery, but also the long-term impact of surgery physically and psychologically.

The dynamic process for couples in this study began at the point of diagnosis and continued when beginning a decision making process around the type of surgical procedure to undergo; at this point a ‘togetherness’ between partners was expressed in the narratives. The couples later talked of difficulties discussing body image and sexual intimacy issues with their partners despite strong supportive relationships, this created a narrative around ‘pulling away’ where couples’ accounts suggested less emotional or verbal intimacy. There was discrepancy between some couples on the usefulness or appropriateness of discussing these intimate issues. Shared views on the utility of open communication have been shown to result in increased communication; however, in couples where views are not shared, difficulties in communicating have been demonstrated (Hilton, 1994).

In the theme of the ‘centrality of communication’ the couples highlight, when discussing their present circumstances, the importance of moving forward and building ties through communication with each other. Throughout the process the couples displayed various communication styles, which have been shown in previous research to impact on relationship functioning and distress. Manne et al. (2006) investigated the association between three types of communication strategies which couples use to handle stressors experienced during and after breast cancer treatment. Mutual constructive communication was associated with less distress and more relationship satisfaction for the couples. However, demand-withdrawal communication, where one partner approaches a discussion and the other partner withdraws, was associated with higher distress and lower relationship satisfaction. Where partners both avoided communication about stressors, this was associated with more distress but did not impact significantly on relationship satisfaction. The issue of communication is a key factor in this study. However, there is a lack of research in this area in relation to breast cancer and sexual intimacy, therefore this is an area in need of further investigation.

## Clinical Implications

This study demonstrates the importance of understanding how couples negotiate a breast cancer diagnosis and treatment, and its impact on body image and sexuality within the couple. Whilst the findings of IPA studies cannot be generalised without caution, the findings discussed here are consistent with and elaborate upon previous research and thus provide additional support for the following clinical practices.

Firstly, this research has illustrated the need for clear communication about the process of surgery and recovery. Receiving a diagnosis of breast cancer is often hugely overwhelming. This research suggests that couples have an information deficit in terms of what, when and how they receive information about surgery, and how this information is digested and understood. This information deficit had implications for the couples in this study and may have contributed to difficulties, for the women particularly, in adjusting to their post-surgery physical identity and resulting body image. Therefore, there is a need to improve the preparation phase for women and their families to gain an understanding of the enormity of surgery and what to expect immediately following surgery, for example using a ‘breast gallery’ with couples. This will help to manage expectations for the women and prevent further feelings of loss that are already exacerbated by removal of an existing breast

This research has added to the literature on understanding couples' experiences of body image and sexuality following breast cancer (Wimberly et al., 2005: Holmberg et al., 2001: Hilton et al., 2000). This is useful in demonstrating to couples that partners acceptance of the post-surgery female body is more positive than anticipated by many women. In addition, it has provided new insights into the changing and dynamic nature of communication within relationships.

During the conduct of this study, women and their partners were given the opportunity to discuss their concerns around body image and sexual intimacy. The depth and complexity of these conversations show the necessity of offering psychological support for both the woman and her partner throughout the cancer process, particularly around sexual intimacy and body image. Being able to access therapeutic support, and where necessary specialist psychosexual therapy, will help to maintain a physical, verbal, and relational dialogue between the woman and her body, as well as between the woman, her body, and her partner (Piot-Ziegler, Sassi, Raffoul & Delaloye, 2010).

### Methodological Considerations

A strength of this study was the use of an IPA approach that allowed in-depth exploration of participants' experience. Each individual account was analysed carefully and comprehensively, as it was considered that this would improve the rigour of the study and would help to ensure that participants' experiences were captured. These methods also facilitated a good level of interpretative engagement with the narratives. The small sample size was a strength in allowing time for this depth of analysis and ensuring that the voices of all participants were heard, therefore meeting the idiographic commitment of IPA (Smith et al., 2009). However, the sample cannot be viewed as representative of all women and their partners who have undergone a mastectomy with reconstruction and therefore it cannot be assumed that emergent themes are directly applicable to other couples in the same situation. However, achieving a representative sample is not the aim IPA, which challenges the traditional linear relationship between the number of participants' and the value of research (Reid et al., 2005). IPA offers the researcher a chance to engage with a research question at an idiographic level, in producing in-depth analysis of the accounts of a small number of participants. Any conclusions drawn are therefore specific to the context shared by the particular group of participants.

Another limitation within this study was the method of sampling women and their partners. Whilst the sample was homogenous in terms of the women's experiences, the women differed in terms of the type of breast cancer they were diagnosed with, the time since surgery, type of surgery undertaken, and whether this was the first incidence of breast cancer. These differences need to be considered, however the identification of consistent themes across the couples provides support for the sampling method used and increases the potential transferability of the results. Another consideration is the potential for sampling bias, the couples who agreed to take part in this study may have agreed to take part because, as one participant suggested, they had *'things (they) wanted to get out there'*. However, this study gives in-depth attention to four couple's accounts of the difficulties they have encountered.

## Future Research

The accounts of the couples in this study provide interesting information regarding the experiences of couples following an immediate reconstruction. It would be interesting to investigate the experiences of couples from other surgery options as this was beyond the remit of this study. Future research could explore the experiences of women and their partners who had undergone a mastectomy alone, mastectomy with delayed reconstruction, mastectomy with immediate-delayed reconstruction or a breast conserving lumpectomy to ascertain if their experiences are similar to the couples in this study.

Because of the importance for the women in this study of not feeling prepared for the enormity of surgery, further research could be useful in quantitatively exploring the expectations pre-and post-operative women undergoing immediate reconstructions. Recent research has highlighted the utility of an evidence based ‘breast surgery gallery’ (Kydd, Reid & Adams, 2010) in providing education and assistance in decision making by providing women with age, bra size and ethnicity matched images of women prior to surgery and at various stages up to 12 months post-surgery.

## Conclusion

This research has demonstrated that for women who have been diagnosed and treated for breast cancer and their partners a dynamic process of coming together pulling apart takes place. It also demonstrates the importance of services in considering both members of the couple and their adjustment to post-treatment body image and sexual intimacy.

## REFERENCES

Ananian, P., Houvenaeghel, G., Protiere, C., Rouanet, P., Arnaud, S., Moatti, J.P., …Julian-Reynier, C. (2004). Determinants of patients' choice of reconstruction with mastectomy for primary breast cancer. *Annals of Surgical Oncology, 11,* 762–771.

Anllo, L.M. (2000). Sexual life after breast cancer. *Journal of Sex and Marital Therapy, 26*, 241-248.

Bloom, J.R, Stewart, S.L, Chang, S., Banks, P.J. (2004). Then and now: quality of life of young breast cancer survivors. *Psycho-Oncology. 13*(3), 147–160.

Berglund, G., Nystedt, M., Bolund, C., Sjoden, P.O., Rutquist, L.E. (2001). Effect of endocrine treatment on sexuality in premenopausal breast cancer patients: a prospective randomized study. *J Clin Oncol*. *19*(11), 2788–2796.

Breast Cancer Care. http://www.breastcancercare.org.uk/media-centre/breast-cancer-stats-facts. Accessed 10th April 2010.

Brocki, J. M. and Wearden, A. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, *21* (1), 87 – 108.

Bryan, L. A. (2004). An exploration of the effects of breast cancer on survivors' and partners' female body image and sexuality. *Dissertation Abstracts International Section A: Humanities and Social Sciences 64* (10-A), 3859.

Bukovic, D., Fajdic, J., Hrgovic, Z., Kaufmann, M., Hojsak, I., Stanceric, T. (2005). Sexual dysfunction in breast cancer survivors. *Onkologie* 21(1), 223-228.

Burwell, S.R., Case, L.D., Kaelin, C., & Avis, N.E. (2006). Sexual problems in younger women after breast cancer surgery. *Journal of Clinical Oncology, 24* (18), 2815 - 2821

Carver, C. S., Pozo-Kaderman, C., Price, A. A., Noriega, V., Harris, S. D., Derhagopian, R. P…Moffatt, F. L. (1998). Concern About Aspects of Body Image and Adjustment to Early Stage Breast Cancer. *Psychosomatic Medicine*. *60*(2), 168-174

Dow, K.H. (1995). A review of late effects of cancer in women. *Seminars in Oncology Nursing, 11*, 128-163.

Fergus K.D., & Gray R.E. (2009). Relationship vulnerabilities during breast cancer: Patient and partner perspectives. *Psycho-Oncology*, *18*(12), 1311-1322. doi:http://dx.doi.org/10.1002/pon.1555

Fitch, M., Allard, M., (2007a). Perspectives of husbands with breast cancer: information needs. *Canadian Oncology Nursing Journal 17* (2), 7990. Given, B., & Given, C. (1992). Patient and family caregiver reaction to new and recurrent breast cancer. *Journal of the American Medical Women's Association, 47(5),* 201- 206.

Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, *3* (1), 1 – 26.

Harcourt, D., & Rumsey, N. (2001). Psychological aspects of breast reconstruction: a review of the literature. *Journal of Advanced Nursing, 35* (4), 477-487.

Harrow A., Wells M., Barbour R.S., & Cable S. (2008). Ambiguity and uncertainty: The ongoing concerns of male partners of women treated for breast cancer. *Journal of Oncology Nursing*, 349-356. doi:http://dx.doi.org/10.1016/j.ejon.2008.04.009

Heller, L., Parker, P.A., Youssef, A., & Miller, M.J. (2008). Interactive digital education aid in breast reconstruction. *Plastic and Reconstructive Surgery, 122,* 717–724. doi: 10.1097/PRS.0b013e318180ed06

Hilton, B. A. (1994). Family communication patterns in coping with early breast cancer. *Western Journal of Nursing Research*, *16*(4), 366-391

Hilton, B., Crawford, J., & Tarko, M. (2000). Men's Perspectives on Individual and Family Coping With Their Wives' Breast Cancer and Chemotherapy. *Western Journal of Nursing Research*, *22*(4), 438-459.

Kadmon, I., DeKeyser-Ganz, F., Rom, M., & Woloski-Wruble, A.C.(2008). Social, marital, and sexual adjustment of Israeli men whose wives were diagnosed with breast cancer. *Oncology Nursing Forum, 35* (1), 131 – 135

Keating, N.L., Guadagnoli, E., Landrum, M.B., Borbas, C., & Weeks, J.C. (2002). Treatment decision making in early-stage breast cancer: Should surgeons match patients' desired level of involvement? *Journal of Clinical Oncology, 20,* 1473–1479. doi: 10.1200/JCO.20.6.1473

Lee, C.N., Belkora, J., Chang, Y., Moy, B., Partridge, A., Sepucha, K (2011). Are Patients Making High-Quality Decisions about Breast Reconstruction after Mastectomy? *Plastic & Reconstructive Surgery 127* (1),18-26

Lee, C.N., Hultman, C.S., Sepucha, K. (2010). What are patients' goals and concerns about breast reconstruction after mastectomy? *Ann Plast Surg 64* (5):567-9.

Lewis, F. M., & Hammond, M, A, (1992). Psychosocial adjustment of the family to breast cancer: A longitudinal analysis. *Journal of the American Medical Women's Association, 47*(5), 194-200.

Molenaar, S., Oort, F., Sprangers, M., Rutgers, E., Luiten, E., Mulder, J., de Haes, H. (2004). Predictors of patients' choices for breast-conserving therapy or mastectomy: a prospective study. *Br J Cancer 90*: 2123-30.

National Institute for Health and Clinical Excellence (2009, February). *Early and locally advanced breast cancer: Diagnosis and treatment.* Retrieved June 21st, 2012, from http://guidance.nice.org.uk/CG80/NICEGuidance/pdf/English.

Nissen, Swenson & Kind (2002). Quality of life after postmastectomy breast reconstruction. *Oncology nursing forum* 29 (3) 547 -553

Northouse, L.L. (1994). Breast cancer in younger women: Effects on interpersonal and family relations. *Journal of the National Cancer Institute Monographs, 16,* 693-697,

Office for National Statistics (2005). Long term Breast Cancer Survival, England and Wales, up to 2003. (http://www.statistics.gov.uk/statbase/Product.asp?vlnk=14172&More=Y)

Piot-Ziegler, C., Sassi, M.L., Raffoul, W., & Delaloye, J.F.(2010). Mastectomy, body deconstruction, and impact on identity: A qualitative study. *British Journal of Health Psychology 15*, 479 – 510

Potter, S., Brigic, A., Whiting, P.F., Cawthorn, S. J., Avery, K. N. L., Donovan, J. L., and Blazeby, J. M. (2011). Reporting clinical outcomes of breast reconstruction: a systematic review. *J Natl Cancer Inst 103* (1): 31-46.

Ptacek, J. T., Ptacek, J., & Dodge, K. (1994). Coping with Breast Cancer from the Perspectives of Husbands and Wives. *Journal of Psychosocial Oncology*, *12*(3), 47-72. doi:10.1300/J077V12N03_04

Reid, K., Flowers, P., and Larkin, M. (2005). Exploring lived experience. *The Psychologist*, *18* (1), 20 – 23.

Rowland, J.H., Diosso, J., Holland, J.C., Chaglassian, T.& Kinne, D.(1995). Breast reconstruction after mastectomy: who seeks it, who refuses? *Plastic and Reconstructive Surgery. 95*, 812 – 822.

Rowland J.H., Desmond K.A., Meyerowitz B.E., Belin T.R., Wyatt G.E., & Ganz P.A. (2000). Role of breast reconstructive surgery in physical and emotional outcomes among breast cancer survivors. *Journal of the National Cancer Institute*, *92*(17), 1422-1429.

Shands, M. E., Lewis, F. M., Sinsheimer, J., & Cochrane, B. B. (2006). Core concerns of couples living with early stage breast cancer. *Psycho-Oncology*, *15*(12), 1055-1064. doi:10.1002/pon.1036

Sheppard, L. A., & Ely, S. (2008). Breast Cancer and Sexuality. *The Breast Journal*, *14*(2), 176-181.

Smith, J.A., Flowers, P., and Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. Sage. London

Temple, W.J., Russell, M.L., Parsons, L.L., Huber, S.M., Jones, C.A., Bankes, J., & Eliasziw, M. (2006). Conservation surgery for breast cancer as the preferred choice: a prospective analysis. *J Clin Oncol 24*: 3367-73.

Wellisch, D.K., Jamison, K., Pasnau, R., (1978). Psychosocial aspects of mastectomy:II. the man’s perspective. *American Journal of Psychiatry 135*: 543–546.

Winder, A.E., & Winder, B.D. (1985).Patient counselling: clarifying a woman’s choice for breast reconstruction. *Patient Education and Counselling 7*: 65-75.

# PUBLIC DOMAIN BRIEFING DOCUMENT

## What do we know about the impact of intimate partner or social support on medication adherence? A systematic review

**&**

## How do women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction?

**by**

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# PUBLIC DOMAIN BRIEFING DOCUMENT

This thesis was submitted as partial fulfilment of the requirements of a Doctorate in Clinical Psychology. The document describes both sections of Volume I, which includes a literature review examining the research on the impact of intimate partner or social support on antiretroviral medication adherence for people living with HIV (PLWH) and a qualitative study exploring women and their intimate partners' experiences of body image and sexuality after undergoing a mastectomy and reconstruction for breast cancer.

## Study 1: Literature Review

HIV is now a chronic or long-term illness; however the medication regimes that enable suppression of the virus to below detectable levels are complex and are often not adhered to the optimum level (Murphy, Lu, Martin, Hoffman, & Marelichl, 2002). In the last decade there has been a sharp increase in the number of studies attempting to assess adherence factors for PLWH. The importance of maintaining optimum adherence rates has resulted in clinicians and researchers seeking viable and efficacious strategies for enhancing medication adherence. Research suggests that effective intimate partner or wider social support is one way to intervene that can lead to better adherence to antiretroviral treatment (ART) and improved health outcomes for PLWH (DiMatteo, 2004). Whilst support has been recognised as a factor in a complex picture of medication adherence, there were no studies that attempted to draw together this research with regard to PLWH.

A systematic review was undertaken to describe and synthesise the research conducted from 1996 to the present day to answer three research questions relating to intimate partners, wider social support and psychological interventions involving this support in increasing ART adherence.  Twenty-two papers met the inclusion and exclusion criteria for inclusion in the review. Eight reported on studies focused on intimate partners, a further eight studies discussed wider social support for example friends, families or ‘medicine companions’ and six studies tested the efficacy of an intervention based on intimate partner or social support to increase the medication adherence of people living with HIV. The review found that there are limited studies demonstrating strong relationships between social support and adherence and even less that systematically test the utility of providing social support interventions. Therefore research on increasing the types of intimate partner or social support that have shown promise in increasing adherence is needed to further develop this evidence base.

### Study 2: Empirical Paper

Breast cancer treatment can have a profound impact on women’s body image and sexual functioning. Furthermore, intimate partners feel this impact too. There is limited existing in-depth research on how a woman experiences and understands her body and experiences of sexual intimacy following a mastectomy with immediate reconstruction. Even less is known about how the male partners experience and make sense of this process and how the couple’s views fit together. This study aimed to gain a better understanding from the couples’ perspective, of their experiences of breast cancer surgery and the impact on body image and sexual intimacy.

Eight semi-structured interviews were conducted with four couples where the female had undergone mastectomy with immediate reconstruction following a diagnosis of breast cancer. The interviews explored experiences around diagnosis of cancer, decision making and experiences of body image and sexual intimacy post-surgery and into recovery.

The interviews were analysed using interpretative phenomenological analysis (IPA) which yielded three super-ordinate themes: ‘Cancer as a central threat’, ‘The body becomes a central concern’, and ‘Centrality of communication’. These themes fitted within a process for each couple that was dynamic and changeable, with the focus changing from cancer to the female body, then moving again to focus on building relationships. This study illustrates the positive acceptance partners express of their wives’ post-surgery bodies. This study also highlights the importance of communication and managing surgical expectations during the breast reconstruction process. The theoretical, clinical and research implications are discussed.

## Clinical implications

A number of clinical implications and recommendations result from the findings of these studies. Firstly, the importance of considering and understanding the intimate partners and close social networks of people receiving either HIV medication or undergoing surgery and reconstruction for breast cancer. Secondly, in both populations there is a need for discussion with patients and their partners about the difficulties they may be encountering and the support that could be provided to the couple.

### Future directions.

Research on the types of partner or social support that have shown promise in increasing HIV medication adherence is needed to further develop this evidence base.

In relation to breast cancer further research is needed to explore the dynamics between couples who are at risk of distress due to body image and sexuality issues. Because women in this study did not feel prepared for the enormity of surgery, further research could be useful in quantitatively exploring the expectations of pre- and post-operative women undergoing immediate reconstructions.

### References

DiMatteo, M.R. (2004). Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis. *Health Psychology 23*, 2, 207–218

Murphy, D.A., Greenwell, L. & Hoffman, D. (2002). Factors associated with antiretroviral adherence among HIV-infected women with children. *Women and Health*, 36, 97-111.

# APPENDICES

## Appendix 1 - Instructions for Authors, AIDS and Behavior.

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## Appendix 2 – Instructions for Authors, Psycho-Oncology

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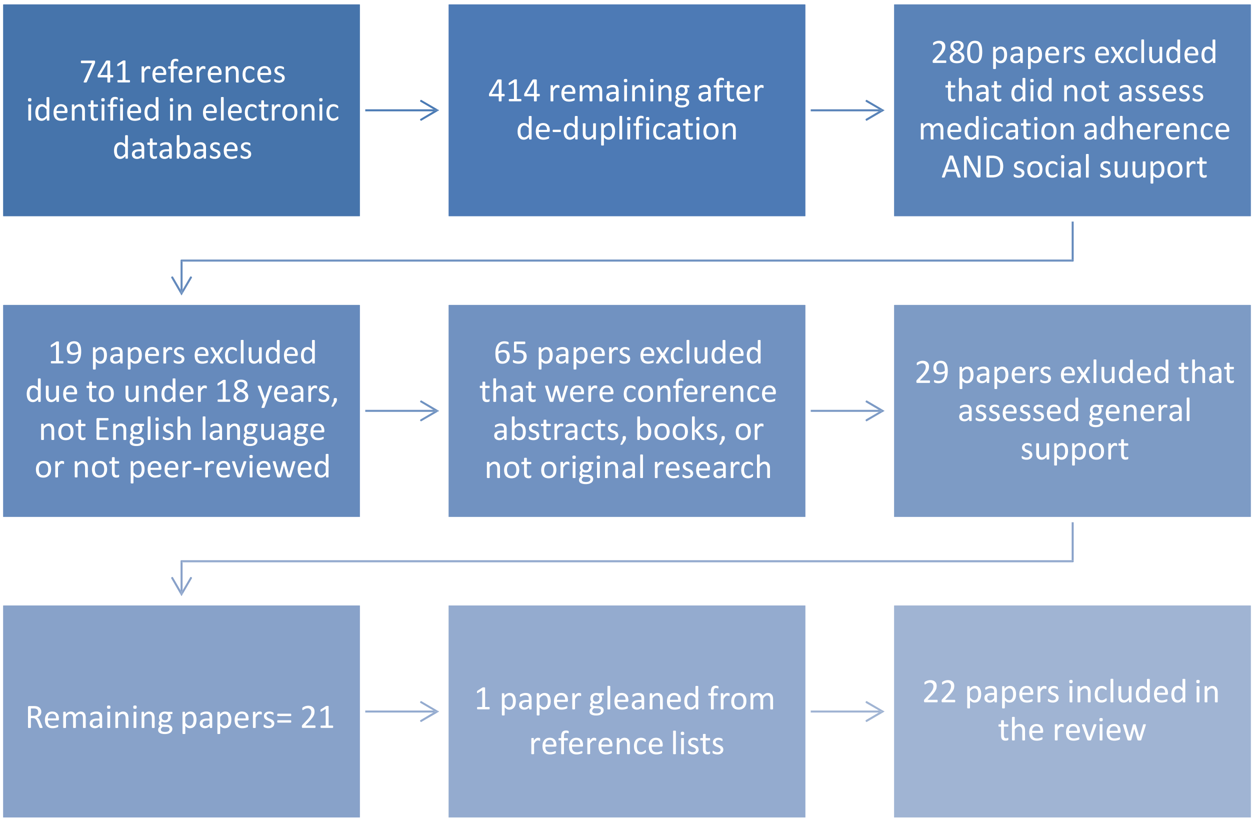
## Appendix 3 – Summary of article search process



## Appendix 4 – Summary tables for each study

**1. Intimate Partner Support**

| Author(s), Year, Country | Study Design | Sample | Study Aims | Intervention, Measures and data collection | Outcomes relating to partners/social support | Limitations |
|---|---|---|---|---|---|---|
| Knowlton, Yang, Bohnert, Wissow, Chander & Arnsten<br>2011a<br>US (Maryland) | Non-experimental - cohort study design<br>(convenience sampling, survey) | n = 154<br>95% African American men<br>48% current illicit drug users<br>17% non-adherent | Looking at negative support and (H1) specific function as compared to structural aspects of social ties, as defined by having informal care versus having a main partner or a larger support network, will be more strongly associated with HAART adherence.<br>(H2) **reciprocity** of support to main supportive ties will be positively associated with adherence. | • Adherence (meds taken divided by meds prescribed over 7 days)<br>• Attitudes to HAART (6 item, 4 point response)<br>• Current drug use (in past 3 months)<br>• Depressive symptoms, *Centers for Epidemiological Studies Depression (CES-D) Scale*<br>• 'How comfortable taking HAART in front of close friends?' (Social comfort level): 4 point scale 0- very uncomfortable to 4 – very comfortable)<br>• Informal care perception: 4 point strongly disagree to strongly agree - *'I have someone who would help care for me if I was sick in bed for several weeks'*<br>• Perceived negative support: 5 item scale with 4 point responses e.g. '*How often have you felt someone close to you resents or acts hostile about helping you?'* from rarely to most or all the time.<br>• Support network size from an inventory (list of names of people who could be relied upon for support over last 6 months)<br>• Main supportive ties - re help with HIV<br>• Reciprocity of support – 7 items 3 point scale (none, some or a lot) on items around different types of support; instrumental (around house), financial or material, socialisation (spent time with), emotional (affection) and contextual (i.e. helping with kids) | (83%) adherence associated with having informal care but not a main partner or a larger number in social network.<br>Adjusted for drug use and favourable attitudes to HAART = adherence associated with interaction between having informal care and reciprocity of support to main supportive ties. i.e. most helpful person in terms of HIV support<br>Comfort taking HAART with friend's assoc with adherence. | Small sample, selection bias, potential response bias, recall bias (self-report). |

| **Author(s), Year, Country** | **Study Design** | **Sample** | **Study Aims** | **Intervention, Measures and data collection** | **Outcomes relating to partners/social support** | **Limitations** |
|---|---|---|---|---|---|---|
| Knowlton, Yang, Bohnert, Wissow, Chander & Arnsten<br>2011b<br>US (Maryland) | Non-experimental - cohort study design<br>(convenience sampling, survey) | *n = 104* ART females<br>(*n* = 80 adherent and *n* = 24 non-adherent) | What has an effect on adherence? IV: **Assessing variables including those related to intimate partners** | • Adherence (meds taken divided by meds prescribed over 7 days)<br>• Attitudes to HAART(6 item, 4 point response)<br>• Depressive symptoms, *Centers for Epidemiological Studies Depression (CES-D) Scale*<br>• Subjective cognitive impairment<br>• Current drug use (in past 3 months)<br>• Current partner (yes/no)<br>• Sero-status of partner<br>• Partner drug use<br>• Living with partner<br>• Intimate partner violence | Having a partner who is HIV positive reduces adherence | Small sample, selection bias, potential response bias, recall bias (self-report). |

| **Author(s), Year, Country** | **Study Design** | **Sample** | **Study Aims** | **Intervention, Measures and data collection** | **Outcomes relating to partners/social support** | **Limitations** |
|---|---|---|---|---|---|---|
| Lopez, Jones, Villar-Loubet, Arheart, & Weiss.<br>2010<br>US (Miami) | Non-experimental - cohort study design<br>(convenience sampling, survey) | *n* =190 men & women (doesn't say how these chosen from main study sample or if couples | 1) Is there a difference in adherence for men and women?<br>2) How much does IPV affect adherence<br>3) Is there a difference in coping strategies between male and females | • Demographics<br>• *ACTG Questionnaire* for <u>adherence to Anti-HIV Medication</u><br>• *COPE* – for <u>AIDS related stressors over last month</u><br>• *Conflict tactics scale* – <u>for assessing IPV</u> | • Whole sample - More IPV + drug coping strategies= reduced adherence<br>• IPV resulted in lower adherence for females but not males<br>• People with higher IPV = increased neg coping strategies | They only recognised the lack of generalisability and didn't state limitations in measures, sampling or strength of results |

| Author(s), Year, Country | Study Design | Sample | Study Aims | Intervention, Measures and data collection | Outcomes relating to partners/social support | Limitations |
|---|---|---|---|---|---|---|
| Wagner, Remien, Carballo-Dieguez & Dolezal.<br>2002<br>US (NYC) | Non-experimental - cohort study design (convenience sampling, survey) | n= 40 serodiscordant couples<br>HIV +tive:<br>• 19 gay men<br>• 14 hetero men<br>• 7 hetero women | To look at variables correlated with adherence | Medication adherence – last 3 days, self-report, time, dose and amount.<br>Potential adherence correlates:<br>• ART efficacy perception (4pt Likert)<br>• Knowledge of therapy & drug resistance (10item T/F)<br>• Psycho-social:<br>• Distress - *Brief Symptom Inventory (Derogatis & Melisarotos, 1983) and BHS (Beck, 1974)*<br>• Dyadic satisfaction – *Subscale of Dyadic Adjustment Scale (Spanier, 1976)*<br>• Sexual satisfaction – *Subscale of Reynolds Brief Sexual Functioning Scale, Reynolds et al., 1988)*<br>• Sexual behaviour and condom use – *Sexual Practices Assessment Schedule, Carballo-Dieguezet al., 1995)*<br>• Drug and alcohol frequency in last 2m | Gay men more adherent in this sample<br>Higher adherence was associated with HIV-negative partner attributing less risk to unprotected anal/vaginal sex within the couple, while lower adherence was associated with a greater likelihood that the couple engaged in unprotected anal/vaginal sex in the last two months. | • Correlational<br>• Small sample<br>• Opportunistic sample<br>• Aims not clearly stated<br>• No ethical info<br>• No power cal reported<br>• No stats tables<br>• Self-reports and possible over reporting of adherence |

| Author(s), Year, Country | Study Design | Sample | Study Aims | Intervention, Measures and data collection | Outcomes relating to partners/social support | Limitations |
|---|---|---|---|---|---|---|
| Do, Phiri, Bussmann, Gaolathe, Marlink, & Wester.<br>2010<br>Botswana (Africa) | Non-experimental - cohort study design<br>(convenience sampling, survey) | n=300 of which:<br>n=100 in each group who were on ARV for:<br>1) 1-6m<br>2) 6-12m<br>3) >12m<br>76% female<br>60% 24-35yrs<br>44% married or cohab (rest single)<br>Pts chosen on first come first recruited basis | To identify psychosocial factors that affect medication adherence<br>**No real social support content except for significance of non-disclosure of HIV to partner associated with poorer adherence** | Measure consisting of:<br>• Demographics<br>• Details of ARV regimes<br>• Performance (physical and QoL)<br>• Perceived stigma and disclosure of HIV<br>• Attitudes and beliefs concerning HIV<br>• Substance use and abuse<br>• Tobacco use<br>• Depression (using BDI)<br>• Pharmacy and H'care related factors (i.e perception of acceptability)<br>• Self-reported adherence to ARV's<br>All data = categorical and frequency data (use of $\chi_2$ for analysis) | Alcohol use, depression, and nondisclosure of positive HIV status to their partner were predictive of poor adherence.<br>Those on ARV's for less than 6 months were poorest adherers (?possibly due to toxicity, adjustment, pill burden) and those on ARV for >12 months (?complacency due to improved physical and cog functioning)<br>No sig- differences found between adh and non-adh on age, gender, education, employment, time to travel to clinic, length of arv treatment, number of people in household, and pill burden. | Hypotheses not directly linked to literature<br>No details: reliability or validity of survey measure or significance for each reported significant result, generally or by group (adherent or non-adherent)<br>No details: between group characteristics. Bias (selection, social desirability, reporting, self-report) |

| **Author(s), Year, Country** | **Study Design** | **Sample** | **Study Aims** | **Intervention, Measures and data collection** | **Outcomes relating to partners/social support** | **Limitations** |
|---|---|---|---|---|---|---|
| Skovdal, Campbell, Nyamukapa & Gregson<br>2011<br>Rural eastern Zimbabwe (Africa) | Quali<br>thematic analysis | n= 53 M&F's on ART<br>+<br>n=25 h'care prov'rs<br>**NOT COUPLES** | To qualitatively explore how male denial of HIV (through concept of hegemonic masculinity) impacts on female partners ability to access and adhere to ART | 37 individual interviews and 5 focus groups. Of which 19 int and 4 FG with patients. 18 int and 1 focus group with nurses.<br>Mix of snowball (using village community health workers), opportunistic (self-selected informants) and typical case sampling (adherers to ART).<br>Sample of farmers, coffee and tea workers.<br>Interview = 1 hour. FG = 2.5 hours. Role playing within FG about good or bad visit to HCF. | 26 codes → 12 basic themes → 3 organising themes.<br>**1-** Social constructions of masculinity - *(male pride, illness = weakness)*<br>**2 -** Men's fear and denial of HIV – (*fears of not being able to live up to male role)*<br>**3 -** Masculinity interfering with married women's ART adherence *(men prevent women from attend or steal drugs)* | Lack of generalisability noted but this is an exploratory study – gives insight into possible cultural perspectives on adherence |

| Author(s), Year, Country | Study Design | Sample | Study Aims | Intervention, Measures and data collection | Outcomes relating to partners/social support | Limitations |
|---|---|---|---|---|---|---|
| Wrubel, Stumbo and Johnson.<br>2008<br>US (San Francisco) | Qualitative exploratory | n=20 gay male couples<br>10 HIV+ couples<br>10 HIV+/- couples | To describe the practical support for ART adherence offered by partners of men with HIV<br>Claim: Practical support more useful than other types of support | 1 to 1 interviews 1.5 hours, simultaneously separately interviewed.<br>Team based analysis (3 in team)<br>Use of index codes to demarcate relevant text and marker codes to note specific actions, attitudes, feelings and experiences. Data coded by 1 person verified by other 2 in team. | 3 kinds of practical support:<br>*<u>Reminding:</u>*3 forms: 1) Regular reminding e.g. when meds due; 2) Situational reminding e.g. when new med regime; 3) Intensive reminding e.g. nagging<br>*<u>Instrumental help:</u>* 4 forms: 1) monitoring meds (e.g. checking); 2) Bringing meds to partner or setting out meds; 3) Organising medication (e.g. mediset box); 4) Ordering & getting med refills (e.g. from chemist).<br>*<u>Coaching:</u>* Situational problem solving or shaping behaviour by reinforcing incremental gains and offering affirmations. | - Small sample<br>- Homogenous – not generalisable<br>- High adherers, no comparison with low adherers<br>- No differences between HIV status couples<br>No contradictory accounts between couples of support offered or received |

| **Author(s), Year, Country** | **Study Design** | **Sample** | **Study Aims** | **Intervention, Measures and data collection** | **Outcomes relating to partners/social support** | **Limitations** |
|---|---|---|---|---|---|---|
| Wrubel, Stumbo and Johnson.<br>2010<br>US (San Francisco)<br>**Linked to Wrubel (2008)** | Qualitative exploratory | n=20 gay male couples<br>10 HIV+ couples<br>10 HIV+/- couples | To examine narrative accounts of offered and accepted support or no-support for adherence to ART.<br>To understand when, why and how support is offered and received and how this affects adherence | 1 to 1 interviews 1.5 hours, simultaneously separately interviewed.<br>_Team based analysis_ (3 in team): Use of index codes to demarcate relevant text and marker codes to note specific actions, attitudes, feelings and experiences. Data coded by 1 person verified by other 2 in team.<br>_Case study:_ data used to write (by 1 researcher) case studies. Looked at dynamics of relationship, in particular health and adherence related support offered or not and accepted or not.<br>_Cross-case analysis:_ Couples grouped according to similarities in patterns of themes, personal meaning, attitudes and actions.<br>HIV status of couple did not appear to affect beliefs about responsibility for ART adherence. | Focused on 2 orientations to ART adherence each with 2 subgroups: **Personal Responsibility** – *viewed adherence as unconnected to relationship* (contains 'my responsibility' and 'his responsibility') **Couples Responsibility -** *viewed adherence as falling to couple and how they defined the r'ship* (contains 'consensual dominance' i.e. one partner in charge and 'mutuality') **Relationships ending:** recognising the changing nature of adherence in relationships and how this is affected when a relationship ends. | Small sample Homogenous – not generalisable (older sample who had been on ART for longer time)<br>High adherers, no comparison with low adherers<br>Cross sectional = No change over time |
| **2. Wider Social Support** | | | | | | |

| Author(s), Year, Country | Study Design | Sample | Study Aims | Intervention, Measures and data collection | Outcome | Limitations |
|---|---|---|---|---|---|---|
| Foster, Nakamanya, Kyomuhangi, Amurwon, Namara, Amuron, Nabiryo, Birungi, Wolff, Jaffar, & Grosskurth<br>2010<br>Uganda (Africa) | Mixed qual and quant. Stratified sampling to ensure balance across gender, treatment arm, and clinical/immunological stage (early or late) | N=1453 MC's (quant)<br>N=40 patients (qual) | Report on the baseline characteristics of 'medicine companions' (MC's) – Who is chosen as an MC?<br>How useful are MC's perceived to be by patients? | **Quantitative data:** Description of medicine companions, demographics and basic information<br>**Qualitative data:** 1-1 interviews with 40 patients on their views of MC's | **Quant outcome** - Women most likely to choose a child to be their MC whereas men more likely to choose their spouse.<br>**Qual outcome** - MC's most useful in first 3 mths for reminders and support but less useful after 6 mths. Convenience, reliability and trust were key factors in choosing an MC | • Lack of info on qualitative data analysis<br>• Very little background literature<br>• No research aims, hypotheses or variables identified.<br>• Descriptive study<br>• Strength and limitations not discussed |
| Author(s), | Study | Sample | Study Aims | Intervention, Measures and | Outcome | Limitations |

| Year, Country | Design | | | data collection | | |
|---|---|---|---|---|---|---|
| Gardenier, Andrews, Thomas, Bookhardt-Murray, & Fitzpatrick.<br>2010<br>US (New York City) | Non-experimental - cohort study design<br>(convenience sampling, survey) | n=56<br>Pts had comorbid MH or SU or adjustment issues | To describe perceived social support in comorbid PLWH in a day care prog and explore diffs between adherent and non-adherent patients | **Measures:**<br>• *Social Provisions Scale* - SPS (Cutrona and Russell, 1987)<br>6 subscales:<br>*(Instrumental Provisions)*<br>- **Reliable Alliance** - Knowledge that one can count on tangible aid when it is needed<br>- **Guidance** - Advice and information from a trusted source<br>*(Emotional Provisions)*<br>- **Attachment** - Closeness and intimacy that fosters a sense of security<br>- **Social Integration** - A sense of belonging to a group with similar interests and concerns<br>- **Reassurance of Worth** - Recognition of one's abilities and competence<br>- **Opportunity for Nurturance** - The feeling that one is needed by others<br>• *AIDS Clinical Trial Group Adherence Interview Questionnaire* (Chesney et al. 2000) | N=28 were classified as adherent and n= 23 were non-adherent.<br>Adherent participants had significantly higher CD4 counts (strong).<br>There was a (weak) positive correlation between adherence and social support (those in the adherent group reported higher levels of overall social support - total scores).<br>Significant positive correlations were found for:<br>• Emotional (overall)<br>• Instrumental (overall)<br>• Guidance<br>• Attachment<br>• Social integration<br>• Reassurance of worth | No causality can be inferred about the program people are engaged with in relation to the significant results<br>Specific clinical sample – not generalisable<br>No Pearson's *r* reported for social support analysis with adherence, only *p* values (which are relatively weak)<br>No randomisation |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and** | **Outcomes relating to** | **Limitations** |

| Year, Country | Design | | | data collection | partners/social support | |
|---|---|---|---|---|---|---|
| Nachega, Knowlton, Deluca, Schoeman, Watkinson, Efron, & Chaisson.<br>2006<br>Townships of Cape Town - South Africa | Qualitative exploratory pilot study | FG – Patients, n=12<br>(11 female, 1 male, all Black African, 11 = straight, 1 gay, HAART duration 3-24months)<br>1-1 with HCP, n=7 (3 women, 4 men, 5 Doctors, 1 TB nurse, 1 HAART nurse) | Through patient and provider perceptions this study aimed to understand how patient selected treatment supports might affect antiretroviral treatment outcomes and to identify key components of support including the social and material resources necessary for promoting high adherence. | Focus group x 2, n=12 (90min)<br>Questions: Norms and practices of health support networks, health seeking behaviours, medical and social problems encountered, experiences taking HAART, and barriers to HAART adherence.<br>Individual in-depth interviews with health care providers, n=7 (60min)<br>Question: What support do you think people on HAART need?<br>From analysis a model emerged of a patient’s treatment support gradually shifting from clinic to home/community sources over time and from a focus on survival and physical health needs to the building of a social support network. | Participants identified the critical forms & sources of support that facilitate adherence and perceived social & material barriers to adherence.<br>• **Short term focus on condition** - first 3 months focused on medical aspects of HIV.<br>• **Long term support focused on empowered living** - less about the medical aspects of HIV and more about maintaining adherence - having necessary motivation, knowledge and support to sustain excellent adherence.<br>• **Key characteristics of tx supporters** - mixed, healthcare providers, social workers, church members or family members. Proximity to patient was a key characteristic of TS.<br>• **Social barriers to disclosure and stigma** - disclosure being a key step in building supportive adherence relationships) | Sampling stated as random, but more likely opportunistic (from waiting area).<br>Data from focus group not audio recorded as consent not given, analysis relied on field notes.<br>No rationale for analysis chosen (content analysis) and no detailed description of analysis process.<br>Generalisability to other parts of South Africa, Africa and beyond.<br>Conclusion infers results have an impact on adherence but this study didn’t systematically assess adherence, just qualitative self-reported barriers to adherence |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and** | **Outcomes relating to** | **Limitations** |

| **Year, Country** | **Design** | | | **data collection** | **partners/social support** | |
|---|---|---|---|---|---|---|
| Power, Koopman, Volk, Israelski, Stone, Chesney, & Spiegel.<br>2003<br>US (Northern California) | Non-experimental - cohort study design (convenience sampling, survey) | n=73<br>53% male<br>60% white<br>47% gay & 45 & straight | Examine relationships between adherence and social support (3 types) and use of 2 coping skills (denial and SU)<br>****measures social support but doesn't assess social supporters*** | • *ACTG (AIDS Clinical Trials Group) Questionnaire for Adherence to Anti-HIV Medications* (4 days; Chesney et al., 2000).<br>• *Stanford Psychosocial Oncology Questionnaire* to assess demograhpic variables<br>• *UCLA Social Support Inventory* (Schwarzer, Dunkel-Schetter and Kemeny, 1994) – Assessed advice, assistance, reassurance and listening on a seven point Likert scale: 1 = very dissatisfied to 7= very satisfied)<br>• *Brief Coping Inventory* (Carver, Scheier, Weintraub, 1989). | Perceived satisfaction with support from a partner was associated with taking antiretroviral therapy as prescribed, whereas satisfaction with support from friends and from family was not significantly related to adherence. | No Power calculations completed<br>Convenience sample<br>No mention of ethics, consent or approval<br>Self-report (adherence)<br>Only small element of social support |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and** | **Outcomes relating to** | **Limitations** |

| **Year, Country** | **Design** | | | **data collection** | **partners/social support** | |
|---|---|---|---|---|---|---|
| Simoni, Frick, Lockhart, & Liebovitz.<br>2002<br>US (Bronx, New York City) | Non-experimental - cohort study design (convenience sampling, survey)<br>Mediation analyses | n=50 (n=31 female & n=19 male). Mean age= 41 y.o. 52% African American & 30% Puerto Rican. 81% Straight, 10% Bisexual & 8% Gay. 49% had a steady sexual partner. 80% <$1000 monthly income | To determine rates and correlates of adherence<br>Hypothesised (in line with theoretical conceptualisation) that social support would be related to adherence through the mediators of self-efficacy in taking meds, negative affective states (depression) and knowledge of HAART regimens. | • *UCLA Social Support Inventory* (Schwarzer, Dunkel-Schetter and Kemeny, 1994)<br>• The Adult AIDS Clinical Trials Group (AACTG) *measure of patient self-report of ART medications* taken over the previous 3 days (Chesney et al., 2000) and *acknowledged non-adherence* questions (x 4) on 4 point Likert e.g. “I often forget to take my HIV medications” 1 (definitely false) to 4 (definitely true).<br>• *Negative affect -* Centers for Epidemiological Studies Depression Scale (Radloff, 1977).<br>• Five *self-efficacy questions* scored on a Likert type response scale from 1 (not at all sure) to 4 (extremely sure).<br>• Also measured spirituality, substance use, side effects, social desirability, ART related knowledge. | Mediation analyses provided partial support for proposed model of social support and adherence.<br>Need for social support was positively correlated with acknowledged non-adherence - this relationship was mediated by reduced self-efficacy (in taking meds) and greater depressive symptomology.<br>Suggesting that those who (as assessed by SS measure) need support from: an affirming other, an information-enhancing relationship, an empathic listener or spiritual relationships were less likely to achieve greater adherence. | Sampling: Small sample, not random selected, not representative of wider HIV population.<br>No ethics information included (consent, approval)<br>Some measures had low reliability |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and** | **Outcomes relating to** | **Limitations** |

| **Year, Country** | **Design** | | | **data collection** | **partners/social support** | |
|---|---|---|---|---|---|---|
| Simoni, Frick, & Huang.<br>2006<br>US (Bronx, New York City) | Longitude-inal study - survey data | n=136 (61 women and 75 men).<br>Inter: n=71<br>SOC: n=65<br>• 55% male<br>• 46% African American<br>• 39% Puerto Rican<br>• Mean age 42y.o.<br>• 83% Straight<br>• 10% Bisexual<br>• 8% Gay.<br>• 81% <$1000 monthly income | To propose a cognitive-affective model of medication adherence based on social support theory and research. | 3 time points: Baseline, after social support intervention at 3 months and at 6 months post-baseline.<br>Measures: **Social Support** - *UCLA Social Support Inventory* (Schwarzer, Dunkel-Schetter and Kemeny, 1994). 4 items Likert style. Pts indicated how satisfied they were with various supports they had received in last 30 days (family, friends, peers, doctors, other clinic staff). **Adherence** - (AACTG) *measure of patient self-report of ART medications* taken over the previous 3 days (Chesney et al., 2000). Dose adherence (% of does taken), pill adherence (correct number of pills taken for each dose) and time adherence (taken at right time)<br>**Negative affect -** *Centers for Epidemiological Studies Depression Scale* (Radloff, 1977), *Psychiatric Symptom Index* (Ilfeld, 1976), & *Perceived Stress Scale* (Cohen et al., 1983)<br>**Spirituality** – *Symptoms of Belief Inventory* (Holland et al., 1998)<br>**ART related knowledge** – 4 Likert response items.<br>Also measured **substance use, side effects, social desirability**<br>Structural Equation Modeling = | Baseline data indicated social support was associated with less negative affect and greater spirituality, which, in turn, were associated with self-efficacy to adhere. Self-efficacy to adhere at baseline predicted self-reported adherence at 3 months, which predicted favourable viral load at 6 months<br>**Therefore, social support not directly related to adherence but had indirect effect through < negative affect (stress, anxiety & depression), > spirituality and > self-efficacy to adhere** | Doesn't justify study design<br>Stated a social support intervention took place (between baseline and 3 months) but no information about what this was. |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | testing and estimating causal relations using a combination of statistical data and qualitative causal assumptions. | | |
| **Author(s), Year, Country** | **Study Design** | **Sample** | **Study Aims** | **Intervention, Measures and data collection** | **Outcomes relating to partners/social support** | **Limitations** |
| Stubbs, Micek, Pfeiffer, Montoya, & Gloyd.<br>2009<br>Mozambique (Africa) | Observational – retrospective case series study.<br>Analysis of case records/medical notes | Total n=434<br>n=375 patients with high adherence >90% time<br>n=59 with low <90% time<br>- 54% female<br>- 40% 30-39 y.o.<br>- 57% 0-7 years education | Evaluate the association between type of tx partner 1) community based - trained community activists, 2) self-selected - family members or friends, 3) none and adherence to HAART in first 6 months of treatment | **Measures:**<br>Adherence: Review of prescription refill charts.<br>Baseline characteristics (age, gender, treatment partner, CD4 count, education, marital status, date started HAART and pregnancy status): Medical charts.<br>***not psychological??*** | In adjusted analysis, patients who had no treatment partner were more likely to have low adherence (compared to self-selected treatment partner). Patients with community-based treatment partners did not have significantly lower adherence than patients with self-selected treatment partners | Small sample with no treatment partner (n=8)<br>No information on treatment partner characteristics or support given, so cannot say what is effective about tx partners.<br>Pharmacy data shows meds picked up but not meds taken. |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and** | **Outcome** | **Limitations** |

| Year, Country | Design | | | data collection | | |
|---|---|---|---|---|---|---|
| Marino, Simoni, & Silverstein.<br>2007<br>US (Bronx, New York City) | Qualitative<br>**(Part of a larger RCT of a peer support intervention aimed at increasing ART adherence, Simoni, 2007).** | n=9 HIV+ peer supporters<br>(mean age 48, 5 female, 2 gay, 6 African American, 2 Latino & 1 White, 5 previous or current substance users)<br>People recruited from peer training sessions (from a total of 12 participants) | What is the experience of providing peer support in ART<br>Qualitative interviews of peers to understand how them providing support may have affected them | 1-1Interviews x 9 and 1 focus group (n=7). Grounded theory. Analysis resulted in the following themes:<br>• **Social Acceptance**<br>- Being with those who are going through the same thing<br>- Feeling accepted in an otherwise isolating disease<br>- Feeling safe in the program<br>• **Reciprocal Support**<br>- Support from peers<br>- Receiving support on many levels<br>- By helping other people I get something in return<br>- Helping other people through example<br>• **Personal Growth and Empowerment**<br>- Feeling entitle enough to talk about disease<br>- Being part of project HAART gave me strength<br>- Change in outlook<br>• **Resistance and Other Challenges**<br>- Obstacles to accepting support<br>- Certain people you cannot help<br>- No control over loss | Peers reported that receiving information about HIV, medication, and community services from other peers lessened their own fears and uncertainties.<br>They also reported that through their role as helpers, they began to feel more personally empowered. They felt more comfortable talking about their disease, and experienced a change in outlook. They also described a change in outlook in relation to themselves, their environment and HIV.<br>This aspect of growth has been supported by Rutter's theory of social support (1987), which reported that self-esteem arose from success in accomplishing tasks and helping others. | No justification for methodology – Grounded Theory<br>Small sample<br>Not representative as it is a specific clinic population in NYC<br>Ethical issues not discussed or details of ethical approval<br>No mention of reflexivity or researcher bias in the analysis of data |
| **3. Intervention Studies** | | | | | | |

| Author(s), Year, Country | Study Design | Sample | Study Aims | Intervention, Measures and data collection | Outcomes relating to partners/social support | Limitations |
|---|---|---|---|---|---|---|
| Remien, Stirratt, Dolezal, Dognin, Wagner, Carballo-Dieguez, El-Bassel, Jung.<br>2005<br>US (NYC) | RCT: parallel groups | *n* = 215 serodiscordant couples.<br>Case *n*=106 Control *n*= 109<br>54% male.<br>62% African American<br>24% Latino | Evaluation of a couple focused adherence intervention.<br>Couples were randomly assigned to one of two conditions: the brief intervention, a four-session couple-focused adherence program, or the control condition, usual care through the medical provider of the HIV-seropositive partner. | Grounded in social action theory (Ewart, 1991) CBT<br>4 x 45-60 min sessions focused on:<br>• Education about treatment and adherence<br>• Identifying adherence barriers<br>• Developing communication and problem solving strategies<br>• Optimizing partner support<br>• Building confidence for optimal adherence<br>Control = treatment as usual<br>Medication adherence using a MEMS cap (Medication Event Monitoring System)<br>HIV biomarkers | Intervention pts showed higher mean medication adherence at post-intervention compared with controls<br>Pts in Couples group significantly more likely to achieve high levels of adherence (> 80%, > 90%, or > 95%) compared with controls. However, effects diminished with time, as seen at follow-up at 3 and 6 months.<br>Conclusion: The SMART Couples program significantly improved medication adherence over usual care (although adherence for many was still suboptimal). Effect diminished over time. | Not a random sample |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and data** | **Outcomes relating to** | **Limitations** |

| **Year, Country** | **Design** | | | **collection** | **partners/social support** | |
|---|---|---|---|---|---|---|
| Feaster, Brincks, Mitrani, Prado, Schwartz, & Szapocznik.<br>2010<br>US (Florida) | RCT (from earlier study)<br>Quant - Mixed design.<br>- 3 conditions including control.<br>- Follow-up at 3, 6, 9 & 18 months.<br>- Intention to treat analysis. | n=156<br>African American women<br>Mean age 36yrs<br>43% never married and not living with sig other | 1) That SET (because of family focus) will be efficacious relative to individual therapy (person centred condition) and a community control condition in improving adherence to HAART<br>2) The effects of SET on adherence would be mediated by effects of SET on family hassles and psychological distress | Participants were randomized to condition (urn randomization procedure, Wei & Lachin [1988] to balance conditions regarding demographics), assessed at baseline and reassessed at 3-, 6-, 9-,and 18-months FU. An intent-to treat design, participants continued to be assessed even if they had dropped out of the SET or PCA interventions<br>**Intervention SET:** 8 sessions of Structural Ecosystems Therapy. (3 stage family therapy techniques)<br>**Intervention PCA:** 8 sessions, no therapeutic orientation, therapeutic relationship was the active ingredient.<br>**Control:** The community control condition was intended to reflect (and control for) the baseline services that African American women who are HIV infected receive in the community. Women in this condition received no services from study.<br>**Measures:**<br>• *Global Severity Index from the Brief Symptom Inventory* (Derogatis, 1993) Measuring psychological distress<br>• *The Hassles Scale* (DeLongis, Folkman and Lazarus, 1988) - revised for AA women to assess family hassles.<br>• *AIDS Clinical Trial Group Adherence Interview Questionnaire* (Chesney et al. 2000) | Using the two-part model SET was significantly more likely to move women towards high levels of adherence (at least 95%) than the person centred condition (hypothesis 1 met) although control condition not significantly different.<br>Family hassles were also significantly reduced by SET but the effect of SET on adherence did not seem related to the change on family hassles (hypothesis 2 was not met) – no mediation | Sampling - All patients currently engaged with services<br>Self-report<br>Original study didn't look at adherence therefore not everyone completed adherence measures (introduced later in study)<br>Sample not clearly described and findings not clearly stated in tables |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and data** | **Outcomes relating to** | **Limitations** |

| **Year, Country** | **Design** | | | **collection** | **partners/social support** | |
|---|---|---|---|---|---|---|
| Murphy, Lu, Martin, Hoffman, & Marelich.<br>2002<br>US (California) | RCT – parallel groups<br>Randomised to intervention or standard care control<br>***** measures social support doesn't assess actual social supporters or include social support in the intervention***** | n= 33 HIV patients<br>Case=17<br>Control=16 | Does a multi-component multidisciplinary intervention increase adherence to ART compared to treatment as usual | **CBT intervention** = 5 sessions (group and individual format):<br>*Session 1:* Group, Psychoeduction about adherence and introduction of behavioural strategies.<br>*Session 2:* Individual, Identify barriers to adherence, develop initial adherence plans with behavioural strategies<br>*Session 3:* Group, Cognitive strategies introduced<br>*Session 4:* Individual, Exercises designed to help participants gain a sense of control over their health care planning<br>*Session 5:* Group, modification and strengthening of individual plans, anticipating challenges in adherence and possible relapse to non-adherence & developing back up plans.<br>**Measures in relation to social support and adherence:**<br>• The Adult AIDS Clinical Trials Group (AACTG) *measure of patient self-report of ART medications* (Chesney & Folkman 1994)<br>• *Adherence Coping Strategies Scale* (Murphy, Rotheram-Borus & Marelich, in press)<br>• *Social Provisions Scale* - SPS (Cutrona and Russell, 1987 | No significant differences in adherence (authors stated that maybe being part of a trial increased adherence for both cases and control)<br>Secondary benefits of increased levels of social support immediately following intervention as measured by Social Provisions Scale.<br>Authors state that the reasons for social support increases could be due to the supportive nature of the group format session or the relationship built with the CBT therapist | Weak effects (*p*=0.4) for social support differences and what about extraneous variables? Can it be said this is an effect of the intervention?<br>Small sample |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and data** | **Outcomes relating to** | **Limitations** |

| **Year, Country** | **Design** | | | **collection** | **partners/social support** | |
|---|---|---|---|---|---|---|
| Simoni, Pantalone, Plummer, & Huang.<br>2007<br>US (Bronx, New York City) | RCT – parallel groups with follow-up | As Simoni et al. (2006)<br>n=136<br>Current clinic patients who were HIV-positive and good adherers = peer mentor intervention. | To determine the efficacy of a peer-led social support intervention involving support groups and telephone contacts compared with standard clinical care to enhance antiretroviral medication adherence. | **Intervention**: 3-month peer support intervention in two parts: 6 twice-monthly 1-hr group meetings at the clinic of all peers and participants (i.e., “peer meetings”) in addition to weekly phone calls from peers to participants. In the group setting, spend face-to-face time with their peer, and other peers and participants. Goal of benefiting from the discussion of the shared experience.<br>**Measures** conducted at baseline, 3 months, and 6 months:<br>• **Viral Load** – taken from medical records at each time-point<br>• **Adherence** - (AACTG) *measure of patient self-report of ART medications* taken over the previous 3 days (Chesney et al., 2000)<br>• **Social Support** - *UCLA Social Support Inventory* (Schwarzer, Dunkel-Schetter and Kemeny, 1994). 4 items Likert style. Pts indicated how satisfied they were with various support they had received in last 30 days (family, friends, peers, doctors, other clinic staff)<br>• **Depressive symptomology** - *Centers for Epidemiological Studies Depression Scale* (Radloff, 1992). 20 items assessing depressive symptoms in the last week. | No between-conditions intervention effects on the primary outcome of HIV-1 RNA viral load or any of the secondary outcomes of adherence, social support or depressive symptoms at immediate postintervention or follow-up.<br>Post hoc analyses within the intervention condition indicated **greater intervention exposure (i.e. more sessions attended) was associated with higher self-reported adherence, higher social support, and lower depressive symptomatology at follow-up**, even after controlling for baseline adherence. | Under power (needed 150 pts, had 136)<br>Sample issues – motivation, complexity, financial reimbursement, trust in peers, low income, ex-drug users.<br>Not generalisable to whole HIV population<br>Not HAART naive so potentially more entrenched non-adherence |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and data** | **Outcomes relating to** | **Limitations** |

| **Year, Country** | **Design** | | | **collection** | **partners/social support** | |
|---|---|---|---|---|---|---|
| Koenig, Pals, Bush, Pratt, Stratford, & Ellerbrock<br>2008<br>US (Atlanta, Georgia) | RCT – parallel groups, with intention to treat analysis | n=226;<br>110 intervention, 116 controls.<br>60% male<br>80% black American<br>Age: 31-43 y.o. Median 37 y.o.<br>47% less than $10k household income<br>58% hetero<br>32% gay<br>60% had low CD4 count (<200) | Does a social support intervention improve adherence and virilogic response in first 6 months of therapy compared to standard care adherence counselling?<br>Intervention drew on ***Problem Solving Theory*** and *5-stage model of problem solving training*. Theoretically drew on ***Self Determination Theory*** and concept of *autonomy support*. | **Intervention:**<br>Included recruitment of *'supportive partners'* (family or friends) who: 1) attended appts with patient and nurse, 2) helped identify barriers to adherence and problems solving strategies, 3) attend informational multi-patient groups**.**<br>**Control:** Standard care adherence counselling - pts watched 10 min video on adherence and support. Also received 2 prep sessions prior to dispensing medications then further sessions on request.<br>**Measures**:<br>Depressive symptoms, perceived stress, and perceived health as assessed at **baseline by face-to-face interview** by the<br>• *Center for Epidemiologic Studies—Depression Scale* (CES–D; Radloff, 1977)<br>• Short form of the *Perceived Stress Scale* (Cohen, Kamarck, Mermelstein, Forsyth, & Goetsch, 1997; Cohen, Kessler, & Gordon, 1995),<br>• *Brief Medical Outcomes Study health and quality of life index* (Bozzette et al., 1995).<br>Plus: MEMS caps, virologic functioning and medical record review. | **Adherence:**<br>The intervention group showed significantly higher adherence than the control group; however these effects diminished with time.<br>**Virilogical response:** outcomes were inconsistent as there was no significant difference between groups as to whether they achieved a 1 log (or undetectable) viral load and no differences between groups for CD4 count. | 38% lost to follow-up by 6 months.<br>Not stated validity or reliability of measures<br>Rationale for RCT not explicitly stated. |
| **Author(s),** | **Study** | **Sample** | **Study Aims** | **Intervention, Measures and data** | **Outcomes relating to** | **Limitations** |

| **Year, Country** | **Design** | | | **collection** | **partners/social support** | |
|---|---|---|---|---|---|---|
| Taiwo, Idoko, Welty, Otoh, Job, Iyaji, & Agbaji.<br>2010<br>Jos, Nigeria (Africa) | RCT: parallel groups<br>Followed up at weeks 12, 24 & 48 weeks | n=499 treatment naive men and women<br>TPA: n=248<br>SOC: n=251<br>35% male<br>65% female<br>54% married (rest single, widowed or divorced)<br>63% had secondary level education or above | To determine the efficacy of patient-selected treatment partners on virologic and adherence outcomes during first-line antiretroviral therapy | Pts randomised to standard of care (SOC) or patient-selected treatment partner-assisted therapy (TPA). Each patient was followed up at weeks 12, 24 & 48 weeks.<br>**Treatment Partner Assisted (Intervention):** In addition to SOC participants chose a treatment partner who attended one adherence education session and was required to observe ingestion of medication, remind for medication pick-ups and assist with reporting side-effects.<br>**Standard of Care (Control):** at start of study participant received a 2 hour adherence education session plus every 28 days the clinic pharmacist provided adherence counselling based on self-reported adherence and adverse effects. Participants who had a detectably viral load at 24 weeks (>400 copies/ml) received intensive adherence retraining with an adherence counsellor.<br>**Data Collection**: demographics, Virologic outcomes (viral load), adherence to drug pick-up, CD4 cell counts, and mortality. | At week 24, undetectable viral load was achieved by 61.7% of patients in the TPA arm versus 50.2% of those receiving SOC (p=0.05. There was no significant difference at week 48: 65.3% versus 59.4% for TPA and SOC, respectively. Residence-to-clinic distance was significantly associated with virologic and adherence outcomes.<br>**Conclusions**: Use of patient-selected treatment partners was associated with improved drug pickup adherence and initial virologic success but had no durable effect on attaining undetectable viral load. | No assessment of treatment partners<br>Treatment partners were optional when receiving HAART, but if no partner selected patient was excluded from study – no information on these participants. |

## Appendix 5 – Full quality checklist example

| QUALITY CRITERIA | PARTNER STUDIES – Quantitative Designs | | |
|---|---|---|---|
| | Remien, Stirratt, Dolezal, Dognin, Wagner, Carballo-Dieguez, El-Bassel & Jung (2005) | | |
| | Quality: ++ Good + Minor issues - Major issues | | |
| | **Questions asked** | **Comments** | **Rating** |
| 1. Title and Abstract | • Does the title reflect the content<br>• Abstract summarises key components (e.g. Aim, Method, Results)<br>• Overall findings presented (Bias of positive results without describing the negative/non-significant findings | • Yes but doesn't state what type of intervention<br>• Yes and states significant findings and diminished effects | ++ |
| 2. Rationale clearly described? | • Does the author(s) describe the current evidence base?<br>• Does the author(s) identify the gaps in the evidence base?<br>• Does the author(s) justify the need for the area of research? | • Yes good introduction giving clear rationale and gaps in existing research | ++ |
| 3. Research aims clearly stated? | • Does the author(s) clearly state what they plan to research?<br>• Are there clearly focused questions/hypotheses identified? | • Aims are stated but not clear research questions | + |
| 4. Ethical issues addressed? | • Does the author(s) state that ethical approval was sought?<br>• Does the author(s) demonstrate an awareness of the ethical issues raised by the study? (e.g. informed consent, confidentiality, how the effects of the study on participants during and after are handled, withdrawal etc.). | • Ethical approval stated and informed consent are stated in participants section | ++ |
| 5. Methodology appropriate to the research question? | • Is the use of quantitative methodology appropriate to the research aims? (e.g. to determine relationships between a number of variables). | • Methodology appropriate to testing the efficacy of a couple based intervention | ++ |
| 6. Study design identified and the rationale for choice evident? | • Does the author(s) clearly state the design of the study?<br>• Does the author(s) justify the research design used? (e.g. longitudinal, cross sectional, cohort etc.). | • Rationale for couples based design and for need for randomisation but no clear justification for an RCT | + |
| 7. Experimental hypotheses stated? | • Does the author(s) clearly state what they expect to find? | • No – just that they are test the efficacy of the intervention – no hypotheses | - |
| 8. Key | • Does the author(s) identify the main | • No variables stated | - |

| | | | |
|---|---|---|---|
| variables identified? | variables (e.g. independent, dependent) investigated in the study? | | |
| 9. Sample population situated? | • Does the author(s) adequately describe the sample (e.g. gender, age, HIV status, ART adherence at baseline etc.) so that the reader can determine validity of findings?<br>• Is it a representative sample of the population? | • Sample described well but the sample was recruited by response to flyers, suggesting sampling bias may be present | + |
| 10. Selection of participants adequately described? | • Does the author(s) describe the context of where the samples were recruited from?<br>• Does the author(s) describe the method of recruitment used? (e.g. the sampling method, how potential participants were approached to take part etc.)<br>• Does the author(s) identify the inclusion/exclusion criteria? | • Yes, clearly described context and method but no inclusion criteria stated and exclusion criteria is contradictory<br>• Flow diagram also presented | + |
| 11. Method of data collection reliable and valid? | • Does the author(s) use measures appropriate for the population group?<br>• Does the author(s) use measures that reflect the desired constructs?<br>• Does the author(s) use measures with good psychometric properties? (e.g. test-retest reliability, inter-rater-reliability, internal reliability (Cronbach's alpha) and internal consistency).<br>• It the time difference between Time 1 and following up subjects long enough (i.e. longitudinal studies)? | • Yes MEMs cap for adherence and biomarkers but no psychological data or couples based data to assess improvements | + |
| 12. Method of data analysis reliable and valid? | • Does the author(s) state which statistic tests were used?<br>• Does the author(s) use statistical tests that are appropriate to the data properties? (e.g. does the data meet the assumptions of the test). Are power calculations given?<br>• Where the statistical tests used appropriate to the research question?<br>• Does the author(s) consider the impact of extraneous variables and correct/adjust/control for these within the analysis process (i.e. regression)?<br>• Does the author(s) provide evidence of statistical findings? (e.g. data within the text, tables etc.).<br>• Does the author(s) state the levels of significance? | • Statistics clearly stated<br>• Power calculation completed<br>• Appropriate tests<br>• Intent to treat analysis<br>• Consideration of variables by backward stepwise regression analyses | ++ |
| 13. Findings | • Does the author(s) explicitly state | • Findings explicitly | ++ |

| | | | |
|---|---|---|---|
| clearly stated? | their findings?<br>• Does the author(s) present the statistical data in a clear manner?<br>• Does the author(s) clearly differentiate between significant and non-significant findings? | stated and clearly presented in table, graph and figures form<br>• Sig and non-sig findings are reported | |
| 14. Comprehensive discussion? | • Does the author(s) summarise the main findings?<br>• Does the author(s) link their findings back to the research aims?<br>• Does the author(s) state the contribution to theory, context and method linking their findings to current literature and/or psychological theory? | • Good detailed summary of findings<br>• Links to research discussed<br>• Good linkage to current literature and practice | ++ |
| 15. Strengths and limitations identified? | • Does the author(s) identify the limitations of the research? (e.g. sample size, recruitment strategies, method of data collection, analysis etc.)<br>• Does the author(s) identify the strengths of the research? (e.g. its usefulness etc.)<br>• Does the author(s) make recommendations for future research? | • Limitations are discussed and implications discussed<br>• Strengths of the research stated despite limitations<br>• Recommendations made to involve partners | ++ |
| 16. Justifiable conclusions made? | • Does the author(s) make conclusions that are supported by their discussions of their findings? | • Conclusions made but perhaps not in line with the results of the study. No conclusion statement | + |

## Appendix 6 - Quality checklists organised by research question

| QUALITY CRITERIA | **PARTNER STUDIES 1 - Quantitative Designs** | | | | |
|---|---|---|---|---|---|
| | Knowlton, Yang, Bohnert, Wissow, Chander & Arnsten (2011a). | Knowlton, Yang, Bohnert, Wissow, Chander & Arnsten (2011b). | Lopez, Jones, Villar-Loubet, Arheart, & Weiss. (2010) | Wagner, Remien, Carballo-Dieguez & Dolezal. (2002) | Do, Phiri, Bussmann, Gaolathe, Marlink, & Wester. (2010) |
| | **Quality:** ++ **Good** + **Minor issues** - **Major issues** | | | | |
| 1. Title and Abstract | + | + | + | + | ++ |
| 2. Rationale clearly described? | ++ | ++ | ++ | - | + |
| 3. Research aims clearly stated? | + | ++ | ++ | - | ++ |
| 4. Ethical issues addressed? | + | + | ++ | - | ++ |
| 5. Methodology appropriate to the research question? | ++ | ++ | ++ | ++ | ++ |
| 6. Study design identified and the rationale for choice evident? | - | - | - | - | + |
| 7. Experimental hypotheses stated? | - | + | ++ | - | ++ |
| 8. Key variables identified? | ++ | ++ | - | + | + |
| 9. Sample population situated? | ++ | ++ | - | + | + |
| 10. Selection of participants adequately described? | + | + | - | + | ++ |
| 11. Method of data collection reliable and valid? | + | + | + | + | + |
| 12. Method of data analysis reliable and valid? | ++ | ++ | + | + | - |
| 13. Findings clearly stated? | + | + | + | + | - |
| 14. Comprehensive discussion? | ++ | ++ | ++ | + | + |
| 15. Strengths and limitations identified? | ++ | ++ | - | + | + |
| 16. Justifiable conclusions made? | + | + | + | + | + |

| QUALITY CRITERIA | **PARTNER STUDIES 2 – Qualitative Designs** | | |
|---|---|---|---|
| | Skovdal, Campbell, Nyamukapa & Gregson (2011) | Wrubel, Stumbo, & Johnson (2008) | Wrubel, Stumbo, & Johnson (2010) |
| | **Quality:** ++ **Good** + **Minor issues** - **Major issues** | | |
| 1. Title and Abstract | ++ | ++ | ++ |
| 2. Rationale clearly described? | ++ | ++ | ++ |
| 3. Research aims clearly stated? | ++ | ++ | ++ |
| 4. Ethical issues addressed? | ++ | + | + |
| 5. Methodology appropriate to the research question? | ++ | ++ | ++ |
| 6. Philosophical background identified? | + | - | + |
| 7. Study design identified and the rationale for choice evident? | + | + | ++ |
| 8. Major concepts identified? | ++ | ++ | ++ |
| 9. Sample population situated? | + | ++ | ++ |
| 10. Selection of participants adequately described? | + | + | + |
| 11. Method of data collection auditable? | ++ | ++ | ++ |
| 12. Method of data analysis credible and confirmable? | ++ | ++ | ++ |
| 13. Reflectivity considered and described? | - | - | + |
| 14. Findings clearly stated? | ++ | ++ | ++ |
| 15. Comprehensive discussion? | ++ | ++ | ++ |
| 16. Strengths and limitations identified? | ++ | ++ | + |
| 17. Justifiable conclusions made? | + | ++ | ++ |

| QUALITY CRITERIA | **SOCIAL SUPPORT STUDIES 1 – Quantitative Designs** | | | |
|---|---|---|---|---|
| | Simoni, Frick, Lockhart, & Liebovitz. (2002) | Power, Koopman, Volk, Israelski, Stone, Chesney, & Spiegel. (2003) | Simoni, Frick, & Huang. (2006) | Gardenier, Andrews, Thomas, Bookhardt-Murray, & Fitzpatrick. (2010) |
| | **Quality: ++ Good + Minor issues - Major issues** | | | |
| 1. Title and Abstract | + | + | + | + |
| 2. Rationale clearly described? | ++ | ++ | ++ | ++ |
| 3. Research aims clearly stated? | ++ | + | + | ++ |
| 4. Ethical issues addressed? | + | - | + | ++ |
| 5. Methodology appropriate to the research question? | ++ | ++ | ++ | ++ |
| 6. Study design identified and the rationale for choice evident? | ++ | + | + | - |
| 7. Experimental hypotheses stated? | ++ | - | + | - |
| 8. Key variables identified? | ++ | ++ | ++ | + |
| 9. Sample population situated? | + | + | + | + |
| 10. Selection of participants adequately described? | ++ | ++ | ++ | + |
| 11. Method of data collection reliable and valid? | ++ | + | ++ | + |
| 12. Method of data analysis reliable and valid? | ++ | ++ | ++ | + |
| 13. Findings clearly stated? | ++ | ++ | ++ | ++ |
| 14. Comprehensive discussion? | + | ++ | ++ | ++ |
| 15. Strengths and limitations identified? | + | ++ | ++ | ++ |
| 16. Justifiable conclusions made? | + | ++ | ++ | ++ |

| QUALITY CRITERIA | SOCIAL SUPPORT STUDIES 2 – Quantitative Design | |
|---|---|---|
| | Foster, Nakamanya, Kyomuhangi, Amurwon, Namara, Amuron, Nabiryo, Birungi, Wolff, Jaffar, & Grosskurth (2010) | Stubbs, Micek, Pfeiffer, Montoya, & Gloyd. (2009) |
| | **Quality: ++ Good + Minor issues - Major issues** | |
| 1. Title and Abstract | + | ++ |
| 2. Rationale clearly described? | - | + |
| 3. Research aims clearly stated? | - | ++ |
| 4. Ethical issues addressed? | + | + |
| 5. Methodology appropriate to the research question? | + | ++ |
| 6. Study design identified and the rationale for choice evident? | + | - |
| 7. Experimental hypotheses stated? | - | - |
| 8. Key variables identified? | - | ++ |
| 9. Sample population situated? | ++ | + |
| 10. Selection of participants adequately described? | ++ | ++ |
| 11. Method of data collection reliable and valid? | NA | ++ |
| 12. Method of data analysis reliable and valid? | + | ++ |
| 13. Findings clearly stated? | + | ++ |
| 14. Comprehensive discussion? | ++ | ++ |
| 15. Strengths and limitations identified? | - | ++ |
| 16. Justifiable conclusions made? | + | ++ |

| | **SOCIAL SUPPORT STUDIES 3 – Qualitative Designs** | |
|---|---|---|
| | Marino, Simoni, & Silverstein. (2007) | Nachega, Knowlton, Deluca, Schoeman, Watkinson, Efron, & Chaisson. (2006) |
| **QUALITY CRITERIA** | **Quality:** ++ **Good** + **Minor issues** - **Major issues** | |
| 1. Title and Abstract | ++ | ++ |
| 2. Rationale clearly described? | ++ | ++ |
| 3. Research aims clearly stated? | ++ | ++ |
| 4. Ethical issues addressed? | - | ++ |
| 5. Methodology appropriate to the research question? | ++ | + |
| 6. Philosophical background identified? | + | - |
| 7. Study design identified and the rationale for choice evident? | - | - |
| 8. Major concepts identified? | ++ | ++ |
| 9. Sample population situated? | ++ | + |
| 10. Selection of participants adequately described? | + | + |
| 11. Method of data collection auditable? | ++ | ++ |
| 12. Method of data analysis credible and confirmable? | ++ | + |
| 13. Reflectivity considered and described? | - | - |
| 14. Findings clearly stated? | ++ | ++ |
| 15. Comprehensive discussion? | ++ | ++ |
| 16. Strengths and limitations identified? | ++ | + |
| 17. Justifiable conclusions made? | ++ | + |

| QUALITY CRITERIA | INTERVENTION STUDIES 1 | | |
|---|---|---|---|
| | Remien, Stirratt, Dolezal, Dognin, Wagner, Carballo-… Jung. (2005) | Feaster, Brincks, Mitrani, Prado, Schwartz, & Szapocznik. (2010) | Murphy, Lu, Martin, Hoffman, & Marelich. (2002) |
| | **Quality:** ++ **Good** + **Minor issues** - **Major issues** | | |
| 1. Title and Abstract | ++ | ++ | + |
| 2. Rationale clearly described? | ++ | ++ | ++ |
| 3. Research aims clearly stated? | + | ++ | ++ |
| 4. Ethical issues addressed? | ++ | ++ | + |
| 5. Methodology appropriate to the research question? | ++ | ++ | ++ |
| 6. Study design identified and the rationale for choice evident? | + | ++ | - |
| 7. Experimental hypotheses stated? | - | ++ | ++ |
| 8. Key variables identified? | - | ++ | ++ |
| 9. Sample population situated? | + | + | ++ |
| 10. Selection of participants adequately described? | + | ++ | ++ |
| 11. Method of data collection reliable and valid? | + | ++ | ++ |
| 12. Method of data analysis reliable and valid? | ++ | ++ | + |
| 13. Findings clearly stated? | ++ | + | ++ |
| 14. Comprehensive discussion? | ++ | ++ | ++ |
| 15. Strengths and limitations identified? | ++ | ++ | + |
| 16. Justifiable conclusions made? | + | ++ | ++ |

| QUALITY CRITERIA | INTERVENTION STUDIES 2 | | |
|---|---|---|---|
| | Simoni, Pantalone, Plummer, & Huang. (2007) | Koenig, Pals, Bush, Pratt, Stratford, & Ellerbrock (2008) | Taiwo, Idoko, Welty, Otoh, Job, Iyaji, & Agbaji. (2010) |
| | **Quality:** ++ **Good** + **Minor issues** - **Major issues** | | |
| 1. Title and Abstract | ++ | ++ | ++ |
| 2. Rationale clearly described? | ++ | ++ | + |
| 3. Research aims clearly stated? | ++ | ++ | ++ |
| 4. Ethical issues addressed? | + | + | ++ |
| 5. Methodology appropriate to the research question? | ++ | ++ | ++ |
| 6. Study design identified and the rationale for choice evident? | ++ | + | ++ |
| 7. Experimental hypotheses stated? | + | + | - |
| 8. Key variables identified? | ++ | ++ | ++ |
| 9. Sample population situated? | + | + | + |
| 10. Selection of participants adequately described? | ++ | ++ | ++ |
| 11. Method of data collection reliable and valid? | ++ | + | ++ |
| 12. Method of data analysis reliable and valid? | ++ | ++ | + |
| 13. Findings clearly stated? | ++ | ++ | ++ |
| 14. Comprehensive discussion? | ++ | ++ | ++ |
| 15. Strengths and limitations identified? | ++ | + | + |
| 16. Justifiable conclusions made? | ++ | + | ++ |

## Appendix 7 - Reflective journal extract

### Reflective Diary

Prior to starting each interview I felt a mixture of excitement and anxiety. I was excited by the process and the potential data I was about to collect in the form of lived experience. However I was nervous about maintaining my role as a researcher using IPA whilst not drifting into my role as a Clinical Psychologist in Training.

I was also anxious that either member of the couple would feel uncomfortable speaking to me about sexual intimacy and body image. I was also nervous of my own ability to discuss these sensitive topics. As a result, after listening back to my first two interviews I became aware that perhaps I jumped in too quickly with questions, not allowing enough silences, for a fear that the participant would have nothing to say or would feel uncomfortable talking about this subject. Being able to reflect on this in supervision and with IPA peers was important in helping me to think about how to approach this in future interviews.

My own feelings and experiences of changes in my body after childbirth occasionally came to mind during interviews with the women in the study. I was mindful of trying to bracket off these thoughts and stay focused on the interview, however this was quite difficult.

I felt a huge amount of empathy with each individual and each couple. I was hugely struck by their willingness to discuss really personal feelings and situations that usually remain private and between two people. I therefore felt a responsibility to do justice to their experience when analysing the data.

## Appendix 10 - Letter to participants – Male & Female

*clinic information omitted*

*Date: May 2011*

Version: F.1
*Name of Participant*
*Address line 1*
*Address line 2*
*Address line 3*

Dear *(insert name of female)*

Invitation to join a research project investigating the experiences of people who have experienced breast cancer

Following the recent telephone conversation/clinic conversation *(delete as appropriate)* you had with *(insert nurse's name),* Cancer Nurse Specialist on *(insert date)* I am inviting you to take part in at study exploring the understanding that women and their partners have of experiencing breast cancer treatment and recovery. I have enclosed an information sheet for you to read with details about the study and what it will involve for you.

We will contact you within the next two weeks to see if you would still like to take part in the study. This will also give you the opportunity to ask questions if you have any.

Thank you for your interest in this study.

Yours sincerely,

| | |
|---|---|
| Jessica Loaring | Dr Darja Brandenburg |
| Chief Investigator | Macmillan Clinical Psychologist |
| University of Birmingham | Good Hope Cancer Service |

*clinic information omitted*

*Date: XX 2011*

Version: M.1
*Name of Partner Participant*
*Address line 1*
*Address line 2*
*Address line 3*

Dear *(insert name of partner)*

## Invitation to join a research project investigating the experiences of people who have experienced breast cancer

Following the recent telephone conversation/clinic conversation *(delete as appropriate)* you had with *(insert nurse's name),* Cancer Nurse Specialist on *(insert date)* I am inviting you to take part in at study exploring the understanding that women and their partners have of experiencing breast cancer treatment and recovery. I have enclosed an information sheet for you to read with details about the study and what it will involve for you.

We will contact you within the next two weeks to see if you would still like to take part in the study. This will also give you the opportunity to ask questions if you have any.

Thank you for your interest in this study.

Yours sincerely,

| | |
|---|---|
| Jessica Loaring | Dr Darja Brandenburg |
| Chief Investigator | Macmillan Clinical Psychologist |
| University of Birmingham | Good Hope Cancer Service |

## Appendix 11 - Information sheet – Male & Female

HEART of ENGLAND
NHS Foundation Trust

**clinic information omitted**

Version: F.1
Date: March 2011

# INFORMATION SHEET FOR FEMALE PARTICIPANTS

## Study Name:
## How do women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction.

### Introduction

Thank you for your interest in this research project. You are being invited to take part in a small research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish. Ask if you have any questions and take your time to decide if you would like to take part.

### What is the purpose of the study?

Breast cancer treatment can have a profound impact on a woman's body image and sex life. Intimate partners who also have to adjust to a diagnosis of breast cancer and the effects of treatment may feel this impact too. But little is known about what women feel about their bodies and how they feel about any changes in sexual intimacy, during and after treatment for breast cancer. Even less is known about how the male partner experiences and makes sense of this process. This study aims to sensitively explore and understand couples views of body image and sexuality to provide crucial information that can help cancer service staff prepare other couples for breast cancer treatment and intimacy in the context of breast cancer.

### If I take part what will I have to do?

To help us with this research project, we ask that you and your partner each take part in an interview with the study researcher. You will be interviewed separately and the interviews can take place at either Good Hope Hospital or the University of Birmingham whichever is easiest for you. Travel expenses (up to £5) and refreshments will be provided. During the interviews we hope to discuss your experiences of breast cancer, the treatment you received and how you felt and continue to feel about your body and sexual intimacy. The interview should last no more than 1.5- 2 hours.

All information shared during the interviews will be confidential and no identifying information will be recorded. Prior to the researcher writing the research report you will be contacted and asked if you would like to review what you have said in the interview and what of this is being used in the report. Some quotes from interviews will be used in the research report to illustrate the experiences of living through breast cancer and associated treatments. These quotes will be anonymous but you may feel uncomfortable about them being written in the report. You will then have the option to have particular quotes excluded from the report, to have all quotes excluded or to take no action.

You will be given the opportunity to receive a brief written summary of the study when the project is completed.

### What will happen if I don’t want to carry on with the study?

Participation in this study is completely voluntary.  You are free to withdraw from the study any time prior to or during the interview and if you wish you will not be contacted by the researcher again. Should you wish to withdraw from the study after being interviewed you will be asked if you are happy for your interview data to continue to be used. The procedure above will be then followed - you will have the option to have particular quotes excluded from the report, to have all quotes excluded or to take no action to remove quotes from the report.

### Are there any risks or disadvantages?

If at any time during or after your interview you become distressed by the nature of the conversation, a Nurse Specialist or the Clinical Psychologist will be available to talk with you. We will also provide you with written details of other support services that may be of use to you.

Once you have completed the interview parts of what you say could be used in the written research report, short segments of interview text will be presented as anonymous quotes, your name will not be included. However, because of the sensitive nature of this study the researcher will meet with you to discuss if any of your quotes are going to be used in the report. If you are not happy for these quotes to be used you can ask for them to be taken out of the report.

No identifiable personal information arising from the interviews will be kept. All identifiable information will be confidential and assigned a participant number to ensure anonymity; this anonymised information will be kept for 10 years.

### Are there any benefits?

We hope that by taking part in this research you will be helping the Cancer Service Psychology and Specialist Nursing Team to develop the care and support service for couples where a partner is contemplating or has undergone a mastectomy with reconstruction. This research also forms part of the Chief Investigator’s qualification towards a Doctorate in Clinical Psychology at the University of Birmingham.

### Who is organising the study and what happens next?

The study is being organised by Jessica Loaring, Chief Investigator and Clinical Psychologist in Training. This is joint project between the Heart of England NHS Foundation Trust and the University of Birmingham. Jessica will contact you shortly to see if you would like to take part in this study. If you would like further information or clarification about any aspect of the study please contact:

Jessica Loaring Chief
Investigator School of
Psychology
University of Birmingham
Edgbaston, B15 2TT
[redacted]

Dr Darja Brandenburg
Macmillan Clinical Psychologist
Cancer Psychology Department
The Cancer Centre

Dr Michael Larkin Senior
Research Tutor School of
Psychology University of
Birmingham Edgbaston,
B15 2TT Telephone: 0121
4146036

Queen Elizabeth Hospital
Edgbaston, B15 2TH
Telephone: 0121 3713617

What if I think there is a problem with the research?
If you have any concerns about the research please feel free to address these with the researcher. You can also speak to Dr Brendan Laverty, Assistant Director of Research and Commercial Services at the University of Birmingham. His contact details can be found below. Alternatively you could contact the Patient Advice and Liaison Service (PALS) at Good Hope Hospital on 0121 424 7889 for confidential advice and guidance.

Dr Brendan Laverty
Assistant Director of Research and Commercial Services
Aitchison Building
University of Birmingham
Edgbaston
Birmingham
B15 2TT
[redacted]

HEART of ENGLAND
NHS Foundation Trust
**Good Hope Hospital**

**clinic information omitted**

Version: M.1
Date: March 2011

# INFORMATION SHEET FOR PARTNERS

## Study Name:
## How do women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction.

### Introduction

Thank you for your interest in this research project. You are being invited to take part in a small research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish. Ask if you have any questions and take your time to decide if you would like to take part.

### What is the purpose of the study?

Breast cancer treatment can have a profound impact on a woman's body image and sex life. Intimate partners who also have to adjust to a diagnosis of breast cancer and the effects of treatment may feel this impact too. But little is known about what women feel about their bodies and how they feel about any changes in sexual intimacy, during and after treatment for breast cancer. Even less is known about how the male partner experiences and makes sense of this process. This study aims to sensitively explore and understand couples views of body image and sexuality to provide crucial information that can help cancer service staff prepare other couples for breast cancer treatment and intimacy in the context of breast cancer.

### If I take part what will I have to do?

To help us with this research project, we ask that you and your partner each take part in an interview with the study researcher. You will be interviewed separately and the interviews can take place at either Good Hope Hospital or the University of Birmingham whichever is easiest for you. Travel expenses (up to £5) and refreshments will be provided. During the interviews we hope to discuss your experiences of breast cancer, the treatment your partner underwent and how that affected you as a couple and how you felt and continue to feel about body image and sexual intimacy. The interview should last no more than 1.5- 2 hours.

All information shared during the interviews will be confidential and no identifying information will be recorded. You will be asked, prior to the researcher writing the research report, if you would like to review what you have said in the interview and what of this is being used in the report. Some quotes from interviews will be used in the research report to illustrate the experiences of living through breast cancer and associated treatments. These quotes will be anonymous but you may feel uncomfortable about them being written in the report. You will then have the option to have particular quotes excluded from the report, to have all quotes excluded or to take no action.

You will be given the opportunity to receive a brief written summary of the study when the project is completed.

## What will happen if I don't want to carry on with the study?

Participation in this study is completely voluntary. You are free to withdraw from the study any time prior to or during the interview and if you wish you will not be contacted by the researcher again. Should you wish to withdraw from the study after being interviewed you will be asked if you are happy for your interview data to continue to be used. The procedure above will be then followed - you will have the option to have particular quotes excluded from the report, to have all quotes excluded or to take no action to remove quotes from the report.

## Are there any risks or disadvantages?

If at any time during or after your interview you become distressed by the nature of the conversation, a Nurse Specialist or the Clinical Psychologist will be available to talk with you. We will also provide you with written details for other support services that may be of use to you.

Once you have completed the interview parts of what you say could be used in the written research report, short segments of interview text will be presented as anonymous quotes, and your name will not be included. However, because of the sensitive nature of this study the researcher will meet with you to discuss if any of your quotes are going to be used in the report. If you are not happy for these quotes to be used you can ask for them to be taken out of the report.

No identifiable personal information arising from the interviews will be kept. All identifiable information will be confidential and assigned a participant number to ensure anonymity; this anonymised information will be kept for 10 years.

## Are there any benefits?

We hope that by taking part in this research you will be helping the Cancer Service Psychology and Specialist Nursing Team to develop the care and support service for couples where a partner is contemplating or has undergone a mastectomy with reconstruction. This research also forms part of the Chief Investigator's qualification towards a Doctorate in Clinical Psychology at the University of Birmingham.

## Who is organising the study and what happens next?

The study is being organised by Jessica Loaring, Chief Investigator and Clinical Psychologist in Training. This is joint project between the Heart of England NHS Foundation Trust and the University of Birmingham. Jessica will contact you shortly to see if you would like to take part in this study. If you would like further information or clarification about any aspect of the study please contact:

Jessica Loaring Chief
Investigator School of
Psychology
University of Birmingham
Edgbaston, B15 2TT
[redacted]

Dr Darja Brandenburg
Macmillan Clinical Psychologist
Cancer Psychology Department
The Cancer Centre
Queen Elizabeth Hospital
Edgbaston, B15 2TH
Telephone: 0121 3713617

Dr Michael Larkin Senior
Research Tutor School of
Psychology University of
Birmingham Edgbaston,
B15 2TT Telephone: 0121
4146036

What if I think there is a problem with the research?

If you have any concerns about the research please feel free to address these with the researcher. You can also speak to Dr Brendan Laverty, Assistant Director of Research and Commercial Services at the University of Birmingham. His contact details can be found below. Alternatively you could contact the Patient Advice and Liaison Service (PALS) at Good Hope Hospital on 0121 424 7889 for confidential advice and guidance.

Dr Brendan Laverty
Assistant Director of Research and Commercial Services
Aitchison Building
University of Birmingham
Edgbaston
Birmingham
B15 2TT
Telephone: 0121 4147618.

## Appendix 12 - Consent form – Male & Female

HEART of ENGLAND
NHS Foundation Trust

**clinic information omitted**

Version: F.1
Date: March 2011

# CONSENT FORM FOR FEMALE PARTICIPANTS

## Study Name:

## How do women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction.

Name of primary researcher: Jessica Loaring

Please initial box

1. I confirm that I have read and understand the information sheet dated March 2011 (version F.1) for the above study and have had the opportunity to ask questions and have these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview without giving any reason and that my medical care or legal rights will in no way be affected. ☐
3. I understand that all information about me that is collected during the study will remain anonymous. ☐
4. I understand that I will have the opportunity to review my interview data (quotes from interview) prior to them being used in the research report and will have the opportunity to have my quotes excluded from the report should I so wish. ☐
5. Following satisfactory approval of the quotations suggested for use I will give permission for these to be used in the research report. I understand that I can decide not to have my quotes included in the report. ☐
6. I agree to take part in the interviews for the above study. ☐

| | | |
|---|---|---|
| ______________________ | ______________ | ______________ |
| Name of Participant (please print) | Signature | Date |

For further information or if you have any questions please contact:
Jessica Loaring [redacted]

** clinic information omitted**

Version: M.1
Date: March 2011

# CONSENT FORM FOR PARTNERS
## Study Name:
## How do women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction.

Name of primary researcher: Jessica Loaring

Please initial box

1. I confirm that I have read and understand the information sheet dated March 2011 (version M.1) for the above study and have had the opportunity to ask questions and have these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview without giving any reason and that my medical care or legal rights will in no way be affected. ☐
3. I understand that all information about me that is collected during the study will remain anonymous. ☐
4. I understand that I will have the opportunity to review my interview data (quotes from interview) prior to them being used in the research report and will have the opportunity to have my quotes excluded from the report should I so wish. ☐
5. Following satisfactory approval of the quotations suggested for use I will give permission for these to be used in the research report. I understand that I can decide not to have my quotes included in the report. ☐
6. I agree to take part in the interviews for the above study. ☐

| | | |
|---|---|---|
| ______________________________ | __________________ | _________________ |
| Name of Participant (please print) | Signature | Date |

For further information or if you have any questions please contact:
Jessica Loaring tel. 0121 414 7124 email. jxl914@bham.ac.uk

**Appendix 13 - Interview schedule – Male & Female**

**Version: F.1**
**Date: March 2011**

## INTERVIEW TOPIC GUIDE
## (Females)

Study Name:
How do women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction.

1. Please can you tell me about the type of breast cancer you were diagnosed with and the surgery you underwent?
   *Possible prompts: What did you consider in making a decision to go with that treatment type? What was that like? How did you feel? How do you think your partner felt about that? In what ways did they express that? What support did you have? What did your partner do that was really helpful at that time? What has been useful?*

2. Can you describe your feelings towards your body prior to surgery?
   *Possible prompts: how would you have described yourself? What did you like about your body? What was important for you? What wasn't so important for you? What do you think your partner thought of your body? What do you think your partner thought you thought or felt about your body?*

3. Can you tell me about your feelings towards your body shortly after surgery?
   *Possible prompts: What was that like? How did you feel? How do you think your partner felt? In what ways did they express that? What has been useful?*

4. How do you feel about your body now?
   *Possible prompts: What do you think about it? Have your thoughts or feelings changed? Would you change anything? What do you particularly like? What have you learnt about yourself?*

5. Can you describe your sexual intimacy with your partner prior to your diagnosis?
   Prompts: *How satisfied were you? What did you like? How did you communicate your needs?*

6. Can you tell me about sex with your partner since your diagnosis and then surgery for breast cancer?
   *Prompts: How has breast cancer and treatment affected your sex life? How has sex changed? When did it change? What is different now, if anything? How do you feel about that? What would you change? What was the most difficult part? What do you like? How did you cope with this? What has been useful?*

7. How would you describe your experiences of sexuality and body image to couples at the beginning of the breast cancer process now that you have lived this experience?

*Prompt: What message would you give them? How do you think that would be useful?*

**Version: M.1**
**Date: March 2011**

## INTERVIEW TOPIC GUIDE
## (Male partners)

### Study Name:
### How do women with breast cancer and their male partners experience and understand sexual intimacy and body image following surgery and reconstruction.

1. Please can you tell me about the type of breast cancer your partner was diagnosed with and the surgery your partner underwent?
   *Possible prompts: What did you and your partner consider in making a decision to go with that treatment type? What was that like? How did you feel? How do you think your partner felt about that? In what ways did they express that? What support did you have? What have you found useful?*

2. Can you describe your feelings towards your partner's body prior to surgery?
   *Possible prompts: how would you have described your partner? What did you like about your partners body? What was important for you? What wasn't so important for you? What do you think your partner thought of your body? What do you think your partner thought you thought or felt about her body?*

3. Can you tell me about your feelings towards your partner's body shortly after surgery?
   *Possible prompts: What was that like? How did you feel? How do you think your partner felt? In what ways did they express that? What has been useful?*

4. How do you feel about your partner's body now?
   *Possible prompts: What do you think about it? Have your thoughts or feelings changed? Would you change anything? What do you particularly like? What have you learnt about yourself?*

5. Can you describe your sexual intimacy with your partner prior to your diagnosis?
   Prompts: *How satisfied were you? What did you like? How did you communicate your needs?*

6. Can you tell me about sex with your partner since your partner's diagnosis and then surgery for breast cancer?
   *Prompts: How has breast cancer and treatment affected your sex life? How has sex changed? When did it change? What is different now, if anything? How do you feel about that? What would you change? What was the most difficult part? What do you like? How did you cope with this? What has been useful?*

7. How would you describe your experiences of sexuality and body image to couples at the beginning of the breast cancer process now that you have lived this experience?

*Prompt: What message would you give them? How do you think that would be useful?*

## Appendix 14 - Example stage 2 & 3 analysis

| **Emerging themes** | **Transcript** | | **Exploratory comments** |
|---|---|---|---|
| | JL | Please can you tell me a little bit about the time where you had the discussion with the medical professionals when you'd been diagnosed with breast cancer, and how you came to the decision to have the surgery that you decided to go with? | |
| | R | The time that I'd been diagnosed? | |
| | JL | Yeah. | |
| | R | That very first point that I was told… | |
| | R | … or the sur--… all related to the surgery? | |
| | JL | Yeah related to the sort of options that you had in terms of surgery. | |
| Lack of control<br>Consultant relationship – power/control<br>Out of the blue, shock.<br>Consumed – engulfed.<br>Setting the bar. | R | Um, the, the, the time that I was told about it, um, at that point there was no discussion about, um, options. I was kind of mainly just told, well, you know, they'll be, um, a period of treatment, we'll see you, um, in clinic, we need to do a biopsy so that was, that was the initial news, you know, which was a bit of a shock. Um, so then that, that gave me about two weeks to get my head round this diagnosis. So when I went back, er, there was the biopsy and I remember all I could think about was anything but chemo, anything but chemo I don't want to have to go through chemotherapy. And the, um, the breast cancer specialist said, "Well you'll have to go through chemotherapy, um, whether you have the mastectomy or you don't." Because when I was saying to him anything but chemo I was saying just give me a mastectomy because I thought it was an either/or. | Lack of control- being ‘just told’, relationship with consultant and clinician control.<br>Out of the blue, shock.<br>All consuming thought, 'all I could think about was anything but chemo’, repeated three times. Chemo perceived as worst-case |
| | JL | Yeah. | |

| | | | |
|---|---|---|---|
| Insufficient information – either/or<br>Disbelief/denial<br>This thing, monster, cancer<br>Persuasive plastic surgeon | R | At that point I didn't really know enough about it. And anyway when I went back for the biopsy results and I had a bit more detail and they said, "Right this grade of cancer and we, we recommend a mastectomy." When, when that came from the cancer specialist I think that really, really kind of hit, hit me hard, you know. That was the first time it became real that they were actually going to remove a breast and that was a possibility. Um, and then discussions followed about lumpectomies so there seemed to be, you know, slowly the options seemed to change, um, and they said well you know there's this other option about having chemo to try and reduce the tumour so that the lumpectomy is, is breast conserving. But I was ad--... I was adamant at that point that this thing, that I could feel needed to come out so I wasn't going to hang around for six months waiting for it to shrink or not. So, um, they did two lumpectomies. They still didn't feel they had enough clearance so they still said, um, you've got to have mastectomy. And I think by the second lumpectomy my breast was so distorted that, um, the, the plastic referred me by this time to the plastic surgeon and the plastic surgeon had somehow convinced me that I would be far better off, um, aesthetically with, um, with a mastectomy and a reconstruction, um...<br>And there's this sort of in your head and this option that when you have a reconstruction you're just going to have a normal looking breast. And so it's so, it's so not like that because he gave me a set of websites to come back and look at. And breast reconstructions yeah they give you, they give you a mass there so that you're not flat chested | scenario, mastectomy preferred over chemo. Disbelief.<br>Attempting to piece together information.<br>Lack of information<br>Specialist with power, when it came from the specialist then she believed it. Use of "hit, hit me hard" - impact, being hit with the diagnosis and treatment, assault.<br>Previous disbelief- adjustment a diagnosis, grading of cancer. Initial soft approach gave way to action + definite action.<br>"Seemed", not real, look like, disbelief, option of breast conserving treatment.<br>"Adamant" so utterly unyielding, this "thing" needed to come out, not wanting to wait.<br>How disappointed did she feel when they said the margins weren't big enough?<br>"Distorted" changing body appearance<br>"somehow" "convinced" ?How did she get here? Finding itself in a place/situation |

how did I get here?

Distress, breast not "normal"

Expectations unfulfilled

Externalised (give you a mass)

Conflict between aesthetics and saving life

If you're old you don't need a breast

on the one side, but, but really they look nothing like what I wanted and was used to looking like. So it was, it was very, very distressing. Um, but my primary concern really was not at that point what I was going to look like, it was about, you know, is this, is this going to save my life then, um, that's, that's what, that's what I'll have to have done. But I'd had an older friend who'd had a mastectomy and she chose not to have reconstruction and she was trying to persuade me not to go for the reconstruction because she felt the surgery was too, too lengthy. And so she came and she physically showed me her, you know, where the breast had been removed and stitched and the prosthesis that she wore and it was fine. But it didn't convince me. I, I felt that at my age, she was in her 70s, I felt that at my age it was still important to me to have a body shape that would allow me to wear what I was used to wearing and dress up in the way that I wanted to dress. And at that point my... the sort of sexual side of it really didn't feature at all because I'd also started on chemo and, you know, everything had just been taken over my whole life was taken over by this thing. Um, so after I had the chemo and I was ready for the surgery and I had to make a decision about did I still want to go through with it, God I'm telling you a story you asked me a question I don't think I've stopped.

suddenly.

Expectation of a "normal" looking breast. Expectations of surgeon and patient very different leading to disappointment/distress. Expectations not heard by surgeon. Ambivalence. Breast not what wanted it versus life-saving treatment. Repeating words very very that that's what what, possibly struggling with the duality of preserving body image and saving life.

Conflict, if you old you don't need a breast.
Persuasion
physically showed – exposed

I know what's best, I will decide on my own

assumption – when you're older it's not important to show off your breasts in clothes. Wanting to keep a sense of normality in terms of wearing what she wanted to wear, otherwise this might be unfair.
Chemo and its effects on sex life, life taken over by "this thing"

Engulfed by cancer, consumed

# Appendix 15- Example stage 4 coding and analysis


Promise of Repair
(not met)
Decision
Expectations
169-178
He told me it's gonna be
Surgery
Not happy with body (straight after surgery)
248-249
I just told him straight away - I'm not happy with my body as down
Surgery
Not being heard (surgeon)
He said yeah everything is fine, but everything wasn't fine
Consideration of feelings - angry that surgeon didn't
446-459
He didn't even want to see why I was complaining
Felt the job wasn't done properly - disappointment of expectation
433-443
If you had done it the way you told me I will need to combat.
Surgery
Expectations not been met
193 to 208
Diagnosis
Didn't want to ops
17-28
That's why I went for immediate recon
Decision
Things change in time - breast hard now, told will go soft (surgeon)
80-183
should give that time
Decision
Expectations - breast misshapen - not happy, distorted image
175-189
He thinks it's OK
Frustration - and not getting help (surgeon)
315-331
He told me that it was really nothing
General dissatisfaction with result throughout
If they did the way I wanted it
Recovery
Reconstruction isn't a magic fix
1563-1576
It isn't a magic wand to fix the fact you have breast cancer
Recovery
Expectations
1477-1484
Not everything goes perfectly
Recovery
Expectations
374-378
Had tummy tuck and thought wow, gonna get rest of body to match but didn't
Sexuality
Externalising
Sexuality
Surgeon - contrast with nurses - insensitivity
790-796
She was a bit rough
Sexuality
Externalising / objectifying own body
825-827
What a fantastic operation
Surgery
Discomfort
456-465
Post surgery process
Post surgery
Surgery
Priorities - differences
688-691
They wanted to finish what they'd started, I didn't wanted
Surgery
Communication discrepancies with surgeon
611-625
He assumed I knew what he was going to do
Surgery
Procedural anxiety - caused by Dr
Canula
communication
bad bedside manner
(Student Dr)
543-558
Surgery
Preparation - Not been properly prepared for operation
661-665
It was bang, bang, bang, done
detachment from person
- registrars language
198-206
Surgery
Regret - 2nd surgery to have nipple done
685-686
Expectations
- can't expect miracles
269-270
- much better than expected
209-221
Recovery
Expectations of functioning breast. Not the (sensitivity)
332-341
Surgeon
"quite pleased with his work"
427-430
= Free tummy tuck.
275-283
Recovery
Expectations
- Surgeon happy
- I was not
183-188
Decision
Surgeon as Salesman
135-138
Decision
Giving you a treat - gratitude, should have
114
Decision
Objectification of breasts by Surgeon
108-115
Decision
Surgeon as parental, masterful
126-129
Decision
Programmed / trained to trust you
112-114
Surgery / Decision
Plastic Surgeon Persuasive
48-50
Decision
Who's decision?
Ultimately Surgeon was power.
131
Decision
Ambivalence around Surgeon good / bad
115-118
Surgery
Expectations not met
Surgery not as expected
139-169
Decision
Not heard by Surgeon
51-61
'on a different page'
Recovery
Too late now Should, regret
190
Matter of fact
Just told - Diagnosis
12-13
Recovery
discomfort with end result - physically
236-243
Surgery
recon damaged
190-193
FEAR
Recovery