

Volume I

Research Component

**Couples' Experiences of Breast Cancer over Time:
A Meta- Ethnography and Interpretative Phenomenological Analysis**

by

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A Thesis Submitted to the University of Birmingham in Partial Fulfilment of the
Requirements for the Degree of Doctor in Clinical Psychology

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Abstract

Introduction

This thesis comprises two chapters. Chapter I is a meta-ethnography of 14 qualitative papers on couples' experiences of breast cancer published between 1955 and 2014. It provides a critical review and model of adaptation processes that couples engage in to make sense of the experience of being diagnosed with breast cancer. It outlines how constructions of 'cancer' and 'the couple' are linked to these processes.

Chapter II is a longitudinal qualitative study addressing two gaps identified in Chapter I: experiences 1) of younger couples (where the woman is diagnosed under the age of 50) and 2) over time. Four couples participated in two separate interviews, approximately six months apart. 16 interviews were analysed using Interpretative Phenomenological Analysis (IPA). Results focused on change over time in three dimensions with a bearing on couples' adaptation: 1) changes in external circumstances as couples moved along the cancer trajectory; 2) changes in the meaning given to 'cancer'; and 3) changes in the way the couples related to each other.

Conclusion: Adaptation to cancer is a relational process that changes over time. Partners need to be more fully integrated into clinical care. Metaphors and meaning-making are linked to couples' adaptation and could be explored in further depth to develop tailored interventions.

Overview

This thesis was submitted in partial fulfilment of the requirements of the degree of Doctor in Clinical Psychology at the University of Birmingham. It comprises two volumes. Volume I consists of the research component of the degree, Volume II of the clinical component.

Volume I is concerned with couples' experiences of breast cancer. It contains three chapters: a literature review, a research paper, and a public dissemination document. The literature review is a meta-ethnography of qualitative literature discussing the experiences of couples when the woman is diagnosed with early stage breast cancer. It provides a critical review as well as explanatory model of the adaptation processes that couples engage in to make sense of the experience of being diagnosed with breast cancer. The research paper provides a qualitative longitudinal analysis of young couples' experiences of early breast cancer, addressing some of the gaps in literature that the meta-ethnography has identified; as well as providing further evidence for the adaptation model it suggested. The public dissemination document provides a brief summary of the first and second chapters. It is written in a more accessible way, free of scientific jargon, to provide an overview of the work for non-specialist audiences.

Volume II contains five Clinical Practice Reports (CPR), which were written to evidence clinical practice development over the three years of the Clinical Psychology training course. CPR I is a psychological case formulation of a 78-year old woman with agoraphobia and panic disorder, which was formulated and discussed using Cognitive Behavioural and Psychodynamic models. CPR II is a service evaluation conducted in a Community Mental Health Service (CMHT) in the West Midlands. It evaluated if the support offered to carers of people newly diagnosed with dementia was in line with clinical guidelines and recommendations. CPR III is a case study which was completed in a medium secure hospital service in the West Midlands. It describes the hallucinations of a 31-year old man, and considered if these were symptom of a psychosis, or whether they could be explained more helpfully as a reaction to traumatic life events. Brief Trauma-Focused Cognitive Behavioural Therapy was used to provide this man with some coping strategies. CPR IV was a single case experimental design. It discussed the use of a behavioural experiment as part of Cognitive Behavioural Therapy provided to a woman who had had cancer. This woman struggled with anxiety due to the uncertainty she faced over her prognosis, and she struggled to recognise the link between her behaviours and emotions, which a behavioural experiment was designed to facilitate. CPR V was an oral presentation of a consultancy project completed as part of a

Critical Community Psychology placement at a Children's Centre in a deprived part of Birmingham. A brief summary and abstract of the presentation are provided.

All potentially identifying markers in the reports, such as names, initials or locations have been altered or omitted to maintain confidentiality.

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CHAPTER I

Literature Review

Cancer, Coping and the Couple: A Meta-Ethnography of Couples Adjusting to Breast Cancer

Abstract

Objective: This meta-ethnography synthesises qualitative literature on the experiences of couples where the woman has been diagnosed with early stage breast cancer.

Method: A systematic literature search of six databases using a set of relevant key words to identify qualitative primary research papers on couple's experiences of early breast cancer identified 14 relevant papers. Using a method called 'reciprocal translation', a conceptual model was developed to reflect the main topics, feelings and processes that are of concern to couples diagnosed with breast cancer, and to place these in a context of constructions of 'cancer' and 'the couple'.

Findings: Constructions of cancer changed over time, after its initial ubiquitous perception as an existential crisis. Couples were variably seen as two individuals or as a dyad, which had consequences for the analysis of data. The three most important topics for couples were body image and sexuality; fear of recurrence, uncertainty and death, and communication within the couple. These were accompanied by feelings of helplessness, fear and anger for the men, and vulnerability, loneliness, and unattractiveness for the women. Both parties also felt overwhelmed and depressed at times. Men expressed a variety of emotions openly. Two main trajectories could be seen in the adaptation process; one defined by an integration of cancer into the couple's life, and one which had avoidance and rejection of the diagnosis as its key features. How these are linked to overall coping remains questionable.

Conclusion: Adaptation to cancer is a relational process. Partners need to be more fully integrated into clinical care.

Background

Almost 50,000 women in the UK are diagnosed with breast cancer every year [1]. Even with a good prognosis, this diagnosis means the severe disruption of a woman's life for a year or more, as she endures invasive and prolonged treatments with severe side effects.

Appropriately, this severe disruption to one's life-course through life-threatening illness has been termed a 'biographical disruption' [2], a term which highlights the all-encompassing and all-consuming nature of this experience as the woman comes to terms with the existential threat that cancer poses, as well as the physical discomforts brought on by the treatments. This 'biographical disruption' does not affect the woman in isolation, but has a ripple effect on her relationships. And yet, extant psychosocial research has often followed medicine's individualistic gaze and focused attention on the woman who has been diagnosed, without much consideration for wider networks, or the woman's immediate family. Even research on the impact of cancer on the women's relationships has often only included the women themselves as participants, rather than her partner or other family members [3, 4].

More recently, this individual focus of the research has been found wanting. In the last decade, psychological research has increasingly highlighted the complexity of psychosocial adaptation to cancer, and contextual psychological theories such as systemic approaches have emphasised that relationship dynamics are key to understanding a woman's breast cancer experiences [5]. Influential models of the impact of cancer have included processes from the level of cells to societal contexts [6]. Research at the macro-level context of social and political discourses has discussed how discourses of breasts as one of the main signifiers of femininity define how the loss of a breast is experienced [7, 8]. On the micro-and meso-level context of personal relationships, a substantial literature has examined the relationship between the stress and coping responses in partners on the basis of the coping theory developed by Lazarus and Folkman [9, 10]. This literature has used phrases like 'dyadic coping' to highlight that coping is a relational activity, and has suggested that there is a significant relationship between patients' and their partners' adjustment to the disease [11-13]. It has also emphasised that couples' roles and responsibilities are challenged as a result of a cancer diagnosis; and that this can provide a challenge for the couple's relationship and their intimacy [14-22], leading to some couples coming closer together and others moving apart [23, 24]. One caveat of the research on dyadic coping has been that it has largely focused on each partner's individual coping response and then linked the two, rather than seeing coping as a completely relational activity, which cannot easily be separated into its individual

components [24, 25]. Furthermore, cancer in this literature is almost uniformly seen as ‘something that happens to the couple’, when a relationship is also an important resource for couples [24]. Partners in satisfying relationships see it as such and seek ways to maintain and improve it, especially when faced with difficult challenges [24]. In this context, cancer can also be seen as “an opportunity to forge a more intimate bond” [24, p. 2543], and a refocus of research literature on relationship processes would facilitate a more holistic understanding of a couple’s adaptation to cancer.

A somewhat artificial separation of the components of the adaptation process to cancer has meant that these research findings are not easily translated into clinical practice. As a result, clinical interventions developed to support couples have often been as much based on clinical experience of the developers as research findings, leading to a large number of varied interventions available. Little is currently known about the efficacy of these interventions [23]. A recent meta-synthesis has suggested that they have “small but beneficial effects” [23]. However, it also highlighted that, theoretical models were lacking in much of the examined literature, that it remains unclear how length or timing of interventions might have affected outcomes, and that in a quarter of studies, outcomes for partners were not reported separately because they were only seen as a factor contributing to the well-being of the patient [23].

Some qualitative literature has attempted to provide a more holistic understanding of a couple’s lived experience. A qualitative framework arguably can more adequately capture the complexities of relationships, which suggests that this body of literature can add important new understandings to the existing canon of quantitative literature on the coping and adaptation process of couples to a diagnosis of breast cancer. However, no attempt has been made to date to synthesise the findings of this literature. To address this omission, this meta-ethnography was conducted of qualitative studies on couples’ experiences of breast cancer. Because the experience of breast cancer can vary dramatically with the prognosis and stage of the disease, only studies on couples where the woman had contracted ‘early’ (‘curable’) disease were included to maintain a clear focus. The primary aim of the meta-ethnography was to develop a synthesis of the experiences couples face when diagnosed with breast cancer. It is hoped that this can aid the development of more tailored interventions for couples.

Methods

Type of literature review

This review provides a literature synthesis following the principles of meta-ethnography outlined by Noblit and Hare [26]. A synthesis of this kind does not consist simply of an aggregate of study findings, but provides an interpretation and explanatory framework. The synthesis follows a seven-step process of ‘reciprocal translation’ (see Figure 1). Key themes from the included studies are extracted and ‘translated into each other’: the shared meaning of similar themes is extracted and interpreted in a way that preserves the original meaning but also creates a new interpretation.

<p>Phase 1: From previous research and clinical work experiences of couples living with breast cancer were identified as an intellectual interest.</p> <p>Phase 2: We conducted a systematic search for relevant qualitative studies.</p> <p>Phase 3: We read the articles, paying particular attention to themes, perspectives, and concepts used by the authors to describe and/or explain couples’ experiences.</p> <p>Phase 4: We developed a tabular format so we could compare studies. We listed key themes in each study.</p> <p>Phase 5: We translated the studies into one another. We examined relations between themes within a study and between studies.</p> <p>Phase 6: We synthesised these translations by determining if some themes could encompass other themes. The synthesis took the form of a ‘reciprocal translation.’ That is, similar studies made it possible for each study to be translated into the themes of others and vice versa.</p> <p>Phase 7: We wrote this article so that our meta-ethnography could be published.</p>
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Figure 1. Phases of meta-ethnography

Systematic literature search

For phases one and two (development of the review focus, and literature search), a search was conducted in six databases, PubMed, PsycINFO, Web of Science, Embase, OVID Medline and CINAHL (Cumulative Index to Nursing and Allied Health Literature). The search used a combination of Medical Subject Heading (MeSH) terms and keywords, which had been identified on the basis of initial scoping searches as most relevant (see Table 1).

	Search Term
1	Breast cancer
2	Breast tumor
3	Breast tumors
4	Breast tumour
5	Breast tumours
6	Breast neoplasms [MeSH]
7	Carcinoma breast
8	Carcinoma mammary
9	'Breast Cancer' #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8
10	Spouses [MeSH]
11	Marriage [MeSH]
12	Interpersonal Relations [MeSH]
13	Marital Relationship
14	Dyad*
15	Spouse*
16	Partner*
17	Husband*
18	'Relationship' #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR 17#
19	#9 AND #18
20	Psychol*
21	Psychology and Psychiatry [Majr]
22	Adaptation, Psychological [MeSH]
23	Psychology [MeSH]
24	Qualitative Research [MeSH]
25	Experience*
26	Nursing Methodology Research [MeSH]
27	'Psychology' #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26
28	'Breast Cancer' AND 'Relationship' AND 'Psychology' #9 AND #18 AND #27
	FILTERS: English, German language only

Table 1. PubMed search terms.

Databases were searched in April 2013, and a title-sift performed. Potentially relevant articles from each database were downloaded to a reference manager (Endnote Version X5 [27]) and all abstracts read. The full text of these articles were acquired and checked for relevance in accordance with the inclusion criteria. The reference lists of all included studies were searched for additional studies. A forward citation check was also performed on PubMed,

Web of Science and PsycINFO. All references were kept in the reference manager and a search log used to detail the number of studies retrieved and included at each stage (see flowchart Figure 2). A further search was performed in April 2014 to check if any new relevant studies had been published. No further relevant studies were found.

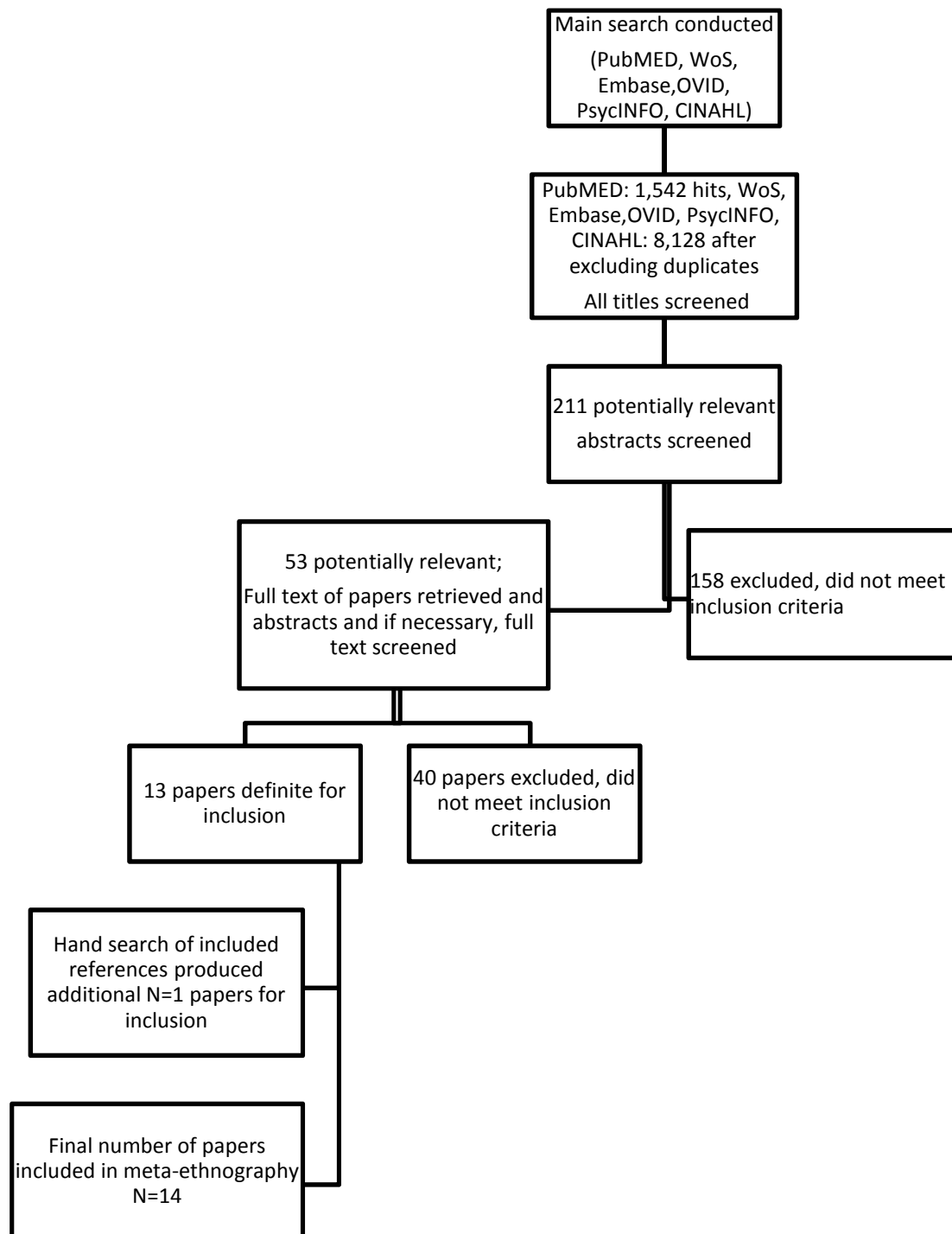


Figure 2. Flowchart Search Strategy.

Inclusion and exclusion criteria

Studies were included if they met the following criteria: (i) study population: couples in a heterosexual relationship where the woman has been diagnosed with early breast cancer; - early breast cancer was defined as any stage cancer but excluding those with recurrent, metastatic or terminal diagnoses (ii) topic: couples' experiences of breast cancer; (iii) design: qualitative or mixed-methods studies with a clearly discernible qualitative analysis component; (iv) language and date of publication: English or German language studies published from 1955 to April 2014. Studies had to be peer-reviewed and discuss primary research.

Studies were excluded if they did not meet the above criteria, for instance if, (i) the study focused on female partners only; (ii) the study focused on women with recurrent or metastatic breast cancer only, or women at risk of developing breast cancer; (iii) studies including mixed cancers and/or caregivers where experiences of partners of breast cancer were not discernible. Given the limited papers available, every effort was made to include as many papers as possible. Papers were included if they also discussed other populations, for example, if they included women with recurrent breast cancer in addition to women with primary breast cancer, as long as the data relevant to this study could be extracted separately.

One reviewer (EA) screened all papers for inclusion, and a second reviewer (EG) conducted an independent check on a quarter of all papers to check for accuracy. Two reviewers (EA and EG) read all papers and agreed on inclusion of each paper.

Quality appraisal

The studies included in the review were subjected to a quality appraisal to ascertain the methodological rigour applied to the study process, and to see if any papers ought to be excluded due to particularly low scores. For this purpose, two sets of quality criteria were chosen which have been used in a previous meta-ethnography [28]. The first set, by Dixon-Woods et al. [29] provides a general assessment of the overall quality of the included papers, with questions mainly focused on the design of studies (see Figure 3).

<ol style="list-style-type: none"> 1. Are the aims and objectives of the research clearly stated? 2. Is the research design clearly specified and appropriate for the aims and objectives of the research? 3. Do the researchers provide a clear account of the process by which their findings were produced? 4. Do the researchers display enough data to support their interpretation and conclusions? 5. Is the method of analysis appropriate and adequately explicated? <p>Documents were rated 5 if all questions were answered in the affirmative, 4 if the method or analysis or sample were not clearly outlined or 3 if both the method or analysis and sample were poorly described.</p>

Figure 3. Quality appraisal criteria for empirical papers (Dixon Woods et al., 2006).

For results of this appraisal see Table 2.

Author	aims/ object ives	research design	process account	enough data	appropri ate analysis	TOTAL
Antoine et al., 2012	y	y	y	y	y	5
Chung & Hwang, 2012	y	y	y	y	y	5
Fergus & Gray, 2009	y	y*	y	y	y	5
Holmberg et al., 2001	y	y*	y*	n	n	3
Kayser et al., 2007	y	y	y	y	y	5
Mak Wai Ming, 2002	y	y*	y	y	y	5
Miller & Caughlin, 2013	y	y	y	y	y	5
Morgan et al., 2005	y	y	y	y	y	5
Northouse, 1989	y	y	y	y	y	5
Picard et al., 2005	y	y	y	y	y	5
Pistrang et al., 1997	y	y	y	y	y	5
Shands et al., 2006	y	y	y	y	y	5
Skerrett, 1998	y	y	y	y	y	5
Zunkel, 2002	y	y	y	y	y	5

*But insufficient detail given about theoretical framework

Table 2. Quality appraisal Dixon-Woods et al. (2006)

The second set of quality appraisal criteria supplements this overall assessment with more nuanced and specific methodological questions that were developed for this purpose by Adams et al. [28] (see Figure 4).

1. Was the recruitment (and resulting sample) specific to the study reported? (As opposed to a report of a sub-sample of a wider study, which is potentially a less rigorous design because the analytic frame is developed after the data was collected, not before).
 2. Does the interview guide or prompting enable the interviewee to raise their own topics or were they raised, and thus introduced, by the researcher?
 3. Did the authors make it explicit how they interpreted the data and what if any, theoretical framework they used?
 4. Did the authors acknowledge social and cultural factors (e.g. social class, ethnicity) in their analysis?
 5. Are strategies employed to verify the coherence of the interpretation and analysis of data (for instance, were strategies such as triangulation used, or was the analysis discussed with user representatives to verify ecological validity)?
- Documents were rated 5 if all questions were answered in the affirmative, 4 if only 4 questions were answered in the affirmative, and so on, with 0 indicating the weakest quality of paper based on these additional appraisal issues.

Figure 4. Additional quality appraisal criteria

The results from this appraisal are in Table 3 below.

Author	Recruit ment specific ¹	Inter view open	Theo retical frame work?	socio- cultural factors	Verify cation of analysis	TOTAL
Antoine et al., 2012	y	y	y	n	y	4
Chung & Hwang, 2012	y	y	n	y	y	4
Fergus & Gray, 2009	y	y	y	n	y	4
Holmberg et al., 2001	y	y	n	n	y	3
Kayser et al., 2007	n	y	y	n	y	3
Mak Wai Ming, 2002	n	n	n	y	y	2
Miller & Caughlin, 2013	y	y	y	n	y	4
Morgan et al., 2005	y	y	n*	y	y	4
Northouse, 1989	y	n	y	n	y	3
Picard et al., 2005	y	y	y	n	y+	3
Pistrang et al., 1997	n	y	y	n	n	3
Shands et al., 2006	n	y	n	n	y	2
Skerrett, 1998	n	y	y	n	y	3
Zunkel, 2002	n	y	y	n	y	3

¹'no' = recruited from pool of larger study/clinical trial/ mixed methods; *used theoretical approach for data analysis but no wider interpretative theoretical framework mentioned; + only study to use validation scheme with participants to check interpretations/analysis

Table 3. Quality appraisal Adams et al. (2011)

In the first quality appraisal, all but one paper [30] received a high-quality score. In the second quality appraisal, the paper in question fared better, and two additional papers had comparatively low scores [31, 32]. These three papers with fairly low scores in either quality appraisal remained included because they did not score exceptionally low on both appraisals.

Data extraction

Phases three and four of the synthesis (familiarisation with the data and extraction of relevant information) saw the extraction of key background information as well as the theoretical framework, key findings and concepts from each paper. This process itself occurred in four stages, which involved numerous re-readings of each publication. Initially, key information was summarised in a template for each paper. As a second step, these individual templates were merged into one summary table. The third step involved extracting key demographic data and looking for overarching headings which could aid a synthesis of disparate themes in the papers. At this stage, key themes in the data were divided into key *topics* of importance for the couples, key *processes* that were described as occurring in the relationship and key *feelings* that were discussed. These were summarised for all studies into a separate table. In addition, the table also held the definitions for ‘cancer’ and also for ‘couple’ that were used or implied in each paper, to provide meta-categories for a contextual understanding of how experiences in the papers were discussed. The fourth step consisted of extracting the topics, feelings and processes from the summary table and to create separate summary tables for these three categories.

Synthesis

The separate tables for topics, feelings and processes formed the basis for steps five and six of the synthesis. In these phases (translation of studies into one another, and final integration of this translation) themes of the papers were initially compared and aggregated for each paper, and then summarised and integrated across papers to form a new, overarching theme. For an example of this step, see Table 9 at the end of the paper, which shows the extraction for the themes ‘body image’ and ‘sexuality’ which were subsequently merged to provide one topic. Themes were included if they were present in at least 25 per cent of the papers, or if they were an important counterpoint to one of these prevalent themes. This initial synthesis framework was discussed with all members of the research team, for validation purposes and to collaboratively develop the main ‘story’ of the synthesis.

Results

Description of studies

Fourteen studies were included. Most studies were from the USA (n=8). Samples in 11 studies consisted overwhelmingly of White, fairly affluent, middle-aged couples with very few participants with different cultural backgrounds. Two studies were on Korean [31, 33]

and one on African-American couples [34]. All studies included women diagnosed with early stage breast cancer. Two studies also included participants with other cancers [35] or metastatic breast cancer [36] but in both cases data pertaining to early breast cancer patients could be extracted separately. Some age data were missing but synthesising the available data, female participants had a mean age of 53.7 years (range= 25-76 years) and males a mean age of 49 (range= 27-78 years). Fewer studies included the males' age, leading to skewed results. Time since diagnosis varied from a few days [37] to 12 years [36], with six studies only including couples in the first year of diagnosis [25, 32, 37-40]. Five studies conducted separate interviews with each partner in the couple [31, 35, 37, 39, 41], five studies conducted joint interviews [25, 32, 33, 38, 42], two studies did both [40, 43], and two studies conducted interviews and focus groups [30, 36]. Northouse [37] conducted two interviews one month apart. For further information see Table 4. For a graphic representation of time since diagnosis see Table 8 (at the end of this chapter), and for a summary of included studies see Table 7.

Study	Sample	Age range		Mean age		Median age		Children	Relationship length (years)	
		Women	Men	W	M	W	M		Mean	Range
Antoine et al., 2012	11 couples	27-51	30-58	39	40			7 couples	12.8	2-23
Chung & Hwang, 2012	7 couples	33-60	39-63	?	?	52		all	Median 26	8-34
Fergus & Gray, 2009	19 W, 11M	37-66	35-62	53.5	50.5			?	W 24.7 M 25.7	W 7-40 M 7-38
Holmberg et al., 2001	10 W, 5M	31-68	33-70	48	55			?	26	1-43
Kayser et al., 2007	10 couples	35-65	?	50.9	?			9 couples	24.3	2-42
MakWaiMing, 2002	83 W, 15 M	35-60	40-72	49	53.07			?	23	1-41
Miller & Caughlin ¹ , 2013	35 W, 25 M	22-86	25-71	51	49			?	23	2-61
Morgan et al., 2005	12 couples	?	?	52.58	54.58			? m= 2.83	24.75	
Northouse, 1989	50 couples	25-76	27-78	50.4	52.3			?	26.5	2-53
Picard et al., 2005	16 couples	?	?	47	49			Y all couples	16	
Pistrang et al., 1997	3 couples	35-49	35-55	41	43			2 couples	11	4-15
Shands et al., 2006	29 couples	29-49	?	41	?			? m= 2	15	3-24
Skerrett, 1998	20 couples	34-73	?	?	?			?	?	1-37+
Zunkel, 2002	15 couples	29-51	30-54	42.73	43.9			Y all couples	17.6	

¹ N=13 with breast cancer; data for all participants, excluded for calculation of synthesis means

Table 4. Demographic information study samples.

Structure of the synthesis

This synthesis focused on five higher order concepts or themes that were important to understanding the cancer experience for couples. Two of these higher order themes, how the 'couple' was constructed, and how 'cancer' was constructed, provide the conceptual backdrop; the remaining three concepts, namely topics, feelings and processes, provide a description and explanation of couples' experiences. These themes are further divided into sub-themes. Sub-themes were derived from the process of reciprocal translation described above, as the most commonly referred to themes in the included studies. For a summary of key concepts see Table 5.

Concepts	Brief explanation
Contextual background	Different ways of constructing ‘cancer’ and the ‘couple’ were used- these require different ways of positioning and ways of being
<i>Constructs of cancer</i>	Ways in which ‘cancer’ was constructed
Crisis	Cancer as... an existential crisis
Challenge	... a challenge, either from god or life itself
Turning point	... an opportunity to change one’s priorities in life
Gift	... a gift, either from god or life
One stressor among many	... either integrated into life at a later phase of the cancer journey, or piling into insignificance given multiple stressors a couple already faces
<i>Constructs of ‘the couple’</i>	Researchers’ different ways of constructing the ‘couple’ meant data were analysed in different ways
Couple as dynamic unit (different to each individual)	‘couple’ is seen as having a separate identity, more than the sum of parts
Two separate individuals	‘couple’ is not seen as much as a unit, each individual partner is the focus
<i>Topics</i>	The most important concerns and issues that participants discussed
Body image and sexuality	How to deal with an altered body, and the significance of sexuality and intimacy
Recurrence, uncertainty and death	Fears of recurrence of the cancer, lingering uncertainty over future outcomes and prognosis, and worries over death
Communication within the couple	Ways in which the couple talked (or not) with each other
<i>Feelings</i>	The most prevalent feelings that were discussed in the included studies
Helpless	Feeling helpless, not knowing what to do
Afraid	Feelings of fear and worry
Lonely	Feeling lonely
Overwhelmed/vulnerable	Feeling overwhelmed by the demands of the disease, and family, and vulnerable
Angry	Feeling angry, with the disease/ the partner or both
Depressed	Feeling depressed, low in mood or very sad
Unattractive	Feeling no longer attractive as a result of breast cancer treatments
<i>Processes – 2 clusters and one further process</i>	Development of adaptation behaviours in the couple over time
Accepting/ integrating: Caring within couple-Sharing feelings-Accepting - Growing together/ Meaning-making	First process, leading of integration of the disease into the couple’s life
Rejecting/ avoiding: Protective withdrawal- Avoiding -Rejecting/ Resenting- Diverging	Second process, characterised by rejection and avoidance of the disease
Normalising (double-edged sword)	A third process which could either support integration of the disease or be linked to avoidance

Table 5. Key concepts of the synthesis

Constructing cancer

Although some of the meanings attributed to cancer in the included studies can appear common place, highlighting these constructions is useful, because the meaning one attributes to cancer has consequences for how one relates to it [44], and according to some research, may influence coping and adaptation to cancer [45]. Contrary to earlier research on the topic [45], it was evident in the included studies how constructions of cancer change over time, with the construct of cancer as an existential crisis ubiquitous in the initial phases of adaptation, around the time of diagnosis [6]. Cancer was at this point perceived as an external and alien phenomenon, imbued with myths and uncertainties that make it all the more threatening. Life can feel as though it is reduced to the day-to-day and all future thought is banished for the moment. However, as couples move through various processes of adaptation, not only the relationship with each other, but also their relationship with the illness changes. Cancer can become a challenge to rise to [35, 38, 40-43], an identity challenge [35] or more broadly, an adjustment challenge [38]. Some couples underwent a transformative process in a context of dissatisfaction with some aspects of their lives. For these couples the cancer might come to symbolise a turning point in their lives [33, 38, 42, 43], or even a gift [25, 33, 42, 43], either with religious connotations as a gift from a spiritual entity, which seemed more relevant for African American couples [42], or life itself. A Korean study also included a reference to cancer being an aid in liberation from strict Confucian hierarchies which had hitherto dominated the couple's life [33]. A number of couples in one study saw cancer as "close to the best thing that ever happened to us" [43].

Seeing cancer as one stressor amongst many was discussed by a few studies [25, 30, 43], in two different ways. One, as time went on and couples got used to the idea of cancer, it might become less remarkable and blend into a long line of difficult life experiences, especially in cases of a good prognosis and a context of old age. Two, for a smaller number of couples, the cancer was devastating, and came at a time where they already felt overwhelmed by other difficulties, amounting to a 'pileup effect' [43].

As indicated here, these differences in constructing the cancer were entwined with different ways of coping with the cancer. As will be discussed below in more detail, the couple's appraisal of the cancer had ramifications for the processes in which couples engaged to adapt to the illness.

Constructing the couple

The majority of studies saw the couple as a dyad made up of two individuals. They discussed the individuals' concerns within the relationship and in relation to each other without

referring to a separate couple identity. In contrast, four papers focused on the couple as a dynamic, relational dyad where the sum was greater than its parts, that is, the couple had a separate ‘couple identity’ distinct from their individual identities [25, 34, 35, 38]. As a consequence, these papers focused on couples’ ‘coping strategies’ or ‘identity challenges’. The distinction is important because the former construct allows a discussion of each partner’s different adaptation strategies and an analysis of how the individuals in a couple might differ and diverge, and how this might impact on the couple’s adaptation as a whole. The latter strategy also has this understanding as a starting point, but rather than stay focused on individual processes, it moves the analysis to a meta-level. Notably, the different conceptualisations were not necessarily related to the studies’ interview strategies: three of the four studies with a focus on ‘couple identity’ used joint interviews, but one did not [35]. This synthesis has integrated both approaches by using a framework in which topics, feelings and processes can be discussed both at an individual and a couple level.

Topics, feelings, and processes

The experiences of couples in the studies could be seen as an ongoing adaptation process from the initial crisis point. This adaptation journey took place within the context of particular issues or topics that couples thought about and had to negotiate, and it was accompanied by particular feelings. The topics and feelings were remarkably similar across the studies, and will be discussed here first to provide some context to the processes described.

Topics

The key topics identified in relation to the couple’s adaptation to the illness were body image and sexuality; recurrence, uncertainty and death; and communication within the couple.

Body image and sexuality

The term ‘body image’ is an unsatisfactory shorthand phrase to describe complex difficulties in relation to the sometimes devastating impact the women had to endure as a result of the cancer and its treatments. Maybe unsurprisingly, physical changes were discussed more frequently by female participants, and descriptions were similar to those provided by studies on women with breast cancer only (rather than couples). Women described a diminished sense of attractiveness, which in turn affected their self-esteem. In some cases, this change was so all-encompassing, it led to what was variably described as a “personal crisis” [38], or a “core identity change” that was affecting women’s sense of womanhood and led to a feeling

of “no longer being adequate in their roles as women and partners” [30]. Interestingly, only one of the Western papers explicitly linked this sense of inadequacy to the pervasive emphasis on women’s breasts as *the* symbol of femininity in Western culture, and then only to express surprise that none of the participants had referred to this directly [30]. However, one of the Korean papers also discussed this issue, stating that it has been shown that ‘Oriental’ women show less distress post-mastectomy, and wondering if this might be related to the fact that in an Asian environment breasts do not seem to have the same sexual symbolism as in the West [31]. In this paper, women were less concerned about the loss of the breast per se, and more dependent on their husband’s feelings as a gauge of their own reaction to the disease [31]. Apart from one study which discussed a husband’s sense of loss for his wife’s breasts [25] all other papers highlighted that men emphasised that their wives altered bodies did not alter their feelings of love, affection and indeed attraction for them.

The vulnerability women experienced in relation to their bodies might have been further exacerbated by the changes in sexual relations that almost all couples experienced during the course of their cancer journey. Both partners described an initial loss of desire, especially during treatment-intensive phases [25, 31, 34-36, 38, 43]. In one study both partners independently discussed their loss of desire with the researchers- but not with each other [30]. In two studies men talked about struggle with these sexual changes, disclosing this for the first time [33, 38]. Notably, in two studies couples specifically talked about a lack of intimacy [36, 38] which is significant because the two are closely linked, and some theorists would go so far as to argue that men especially tend express intimacy mainly by sexual means [46]. In one study, female participants emphasised the importance of creating intimacy and affection in the relationship by other means [30].

Recurrence, uncertainty and death

Fear of recurrence was discussed as a topic in most papers [31-33, 36-41, 43]. It is synthesised together with uncertainty and death, because arguably, these three are linked in a triumvirate of the ultimate existential threat. Fear of recurrence is the topic that was most commonly discussed directly in the couple [32, 33, 37-39, 41, 43], although notably, it was not brought up by any men in the samples. In fact, in some cases men attempted to avoid it. Arguably, the underlying, and often unspoken, larger existential threat is fear of death. Being diagnosed with a potentially life-threatening illness invariably confronted the patients with their own mortality, possibly for the first time. A female participant talked about the fear of not seeing their children grow up [37]. It also confronted the partners with the possibility of losing their loved one, and being on their own, or the sole carer for their children. For some

couples, fears loomed large, but were not spoken about, and felt to be “too powerful to be addressed openly” [30]. In some cases, women wanted to talk but men did not [31, 34, 36]. The authors of these studies tended to see avoidance as detrimental to adaptation. It was noted, for example, that the men’s ability to discuss difficult issues related to the illness openly had been associated in previous studies with post-traumatic growth in both partners [36, 47]. However, cultural differences were observed. Mak Wai Ming emphasised that in traditional Chinese couples, not talking about distress was the norm to ‘save face’ [31], and in Morgan et al.’s study, couples’ open communication was triangulated through the couple’s relationship with god [42]. In many couples, overwhelming fears manifested in a profound experience of ongoing uncertainty even after successful treatment of cancer. Arguably, the false sense of security of a predictable and certain future had been shattered [48] and through the risk of recurrence, cancer and potential death remained an ongoing threat. In some cases, this sense of a changed future was described as “a suspended future” [38, 41] which was particularly acutely felt when the couple was young and the disease also impacted on family planning [41].

Communication within the couple

‘Communication’ is a pertinent topic in any study involving couples, and two main findings repeated across studies might be particularly useful in terms of clinical intervention possibilities. One (see also above), that communication about very difficult and emotive topics like death were difficult [25, 30-33, 36, 38-40, 43], and sometimes avoided between couples [31, 36]. The other main finding was that those couples where each partner had a different communication preference, for example where one partner wanted to talk about their feelings frequently and the other avoided it, seemed to have most difficulties adapting to the diagnosis (for a further discussion see processes below). In relation to this it is important to highlight that although expressive communication style is often seen as health-promoting, a ‘tell all’ approach might not be helpful, and the capacity to be selective and sensitive about what to communicate, and when, seemed more adaptive for couples [43]. Another study suggested that couples that seemed to adapt best were talking openly about the cancer, but did not allow that talk to dominate their daily lives [25]. This supported the adaptation model by Weihs and Reiss [6] who suggested that expressive communication is only helpful in a mutually responsive environment. One study included in this review specifically focused on communication patterns between couples [39]. It provided some nuanced understanding of when communication in couples might be perceived as helpful, detailing that responses to the ‘essence’ of what someone has said are perceived as more supportive than attempts to ‘lighten

the conversation', even if this is intended to be helpful [39]. In these situations, communication is not 'difficult' because the topic is emotive or challenging, but because each partner does not feel listened to or understood, highlighting that intent needs to be separated from the effect of the support given [39].

Feelings

The stereotypical assumption that men do not discuss their feelings as openly as women was not supported by the synthesis of the included studies, even though several individual papers suggested such a pattern of communication between the couple [32, 41, 43]. More feelings were discussed for male participants than the patients, although some feelings were shared between both partners of the couple. The most commonly shared feelings were fear [30-34, 38, 41, 43], feeling overwhelmed or vulnerable [34, 36, 38, 40, 41, 43] or sad/ depressed [30, 31, 33, 40, 43]. Anger was also a commonly discussed reaction. It could be directed at the patient for having cancer [36], at the disease [38, 43], or at each other, blaming each other for the development of the disease or for not having noticed it sooner [33]. Male participants were also angry about changes the cancer brought, for instance in the couple's sex life (here, it could also be tinged with sadness) [30, 31, 33]. The most pervasively noted emotional reaction (in 9/14 studies) was a profound sense of helplessness that the male partners experienced [31-33, 35, 36, 38, 39, 41, 43]. Men found it difficult to see their partners suffer, but felt uncertain of what to do to help, and in some cases, had their efforts rebuffed [36].

The most commonly discussed feelings for women in the study were related to changes in their body image as discussed above. These translated into feelings of being unattractive or undesirable [30, 35, 38, 41], and, in one extreme case, as repulsive to her husband [32]. Although overwhelmingly feelings that were discussed were negative, some positive emotions were also mentioned in almost all papers. Most notably, these were appreciation from the women for their partners' support, and also admiration of the partners for the women's strength, although the negative feelings were much more dominant in the papers' discussions. These topics and feelings were entwined with particular processes.

Processes- relating to cancer and each other

The common metaphor of cancer as a 'journey' emphasises the need to see this process as dynamic and ongoing. Initial research on metaphors and cancer, and the relationship between meaning-making and coping, has either examined coping and related metaphors only at one point in time [49] or found no change in use of metaphors over time [45], but more recent research has emphasised the dynamic nature of the process. Couples have to relate to an

external and existential threat, and engage in a meaning-making process, or as Charmaz put it, people have to “repeatedly rethink how they live and who they are becoming” [50]. Fergus and Gray [36] used a particularly evocative image when they likened the experience of couples to “having to rebuild the ship while navigating a turbulent sea” (p.1314). Overall, the papers used similar ways of describing this adaptation process, and tended to separate it into two distinct trajectories after the initial diagnosis. Indeed, four of the papers included in this synthesis used meta-level concepts to categorise these two types of adaptation processes into clusters [25, 36, 40], or, in one case, the couples into different groups according to their ways of adapting to cancer [43]. Even in papers where the clusters were not explicitly discussed, evidence for both trajectories could be found. Therefore, the two clusters or trajectories will be used here as a useful guide to describe the processes in all papers. Broadly speaking, the two trajectories look as described in Figure 5.

It is noteworthy that a number of papers only hypothesised on the link between these processes and the women’s adaptation, not the couple’s [40]. This paper also highlighted that younger couples seemed to struggle more and be more likely in what the authors termed the ‘problematic’ cluster, maybe due to less time to strengthen their relationship, and the untimeliness of the diagnosis [43].

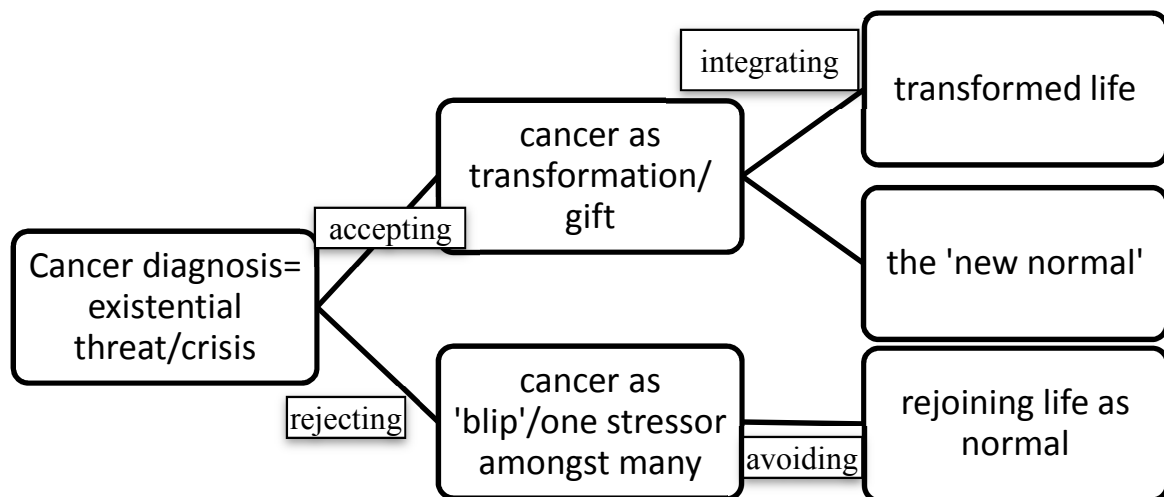


Figure 5. The two trajectories of processes of relating to cancer.

The processes which relate to the two different trajectories, and to the overall process of acceptance versus rejection, are detailed in Table 6, and will be described in more detail here.

Accepting and integrating cancer into the couples' lives

The accepting/integrating way of relating to cancer contained four main processes: supporting and caring within the couple, sharing feelings, accepting the cancer and each other, and growing together. Supporting and caring responsibilities lay heavily with the male partners in the couple, and in the majority of papers, the men embraced this opportunity, providing instrumental support (with household chores, children, practical tasks) [30, 33, 37, 40, 41], generally caring and being responsive to the woman's needs [25, 33, 34, 36, 38, 39, 41], and empathising with her [25, 33, 38-41]. For some men, this meant a considerable shift from their previous behaviour in the relationship, and prompted some men to take steps such as changing jobs or taking early retirement [33, 38]. This seemed to help alleviate these men's sense of helplessness, in some cases to such degree that men spoke about the difficulty of giving up caregiving when the woman felt better [35].

Self-disclosure and sharing of feelings was another important process in this trajectory. It seemed to increase intimacy and promote closeness, but only if both partners in the couple participated and were receptive to each other's feelings [25, 34, 35, 38-41, 43]. Processes of accepting the cancer and each other and growing together and meaning-making went hand in hand. 'Accepting' meant accepting differences in terms of the woman's body, and accommodating change in each other without judgment [25, 33, 34, 36, 43]. Couples described how this process needed active input as well as more passive acceptance. Active input facilitated growing together, and could take the form of actively renewing the commitment the couple had made to each other [38], spending time together without other people or children [32], and nurturing new avenues to express affection [43]. This also contained a process of meaning-making, where couples reflected on the meaning cancer had for them [33] and actively constructed a new meaning of life [38]. This 'new meaning' was often linked to couples emphasising some positive aspects of having gone through the disease [25, 33, 34, 38, 39, 41, 43]. This was not only the case for patients further on from diagnosis, but also in studies focusing on the first 3-18 months post-diagnosis [25, 38, 39]. In some studies, these positive aspects could be seen as empowering to the women, and involved them becoming 'selfish' in the sense of prioritising their own needs more so than previously [33, 41]. For some couples this resulted in a strengthening of the relationship [25] but for others it meant new challenges [41]. In some studies, couples discussed fundamental life changes that were not limited to a shift in women's self-perception and empowerment but described in existential terms as a shift towards a 'more fundamental existence' [41], to be more focused on the 'here and now' [34], to achieve shared dreams [38] and to 'live for the day' [43]. These findings support a widely observed phenomenon that suffering can provide a growth

experience [51]. Given that a number of the included studies focused on the 18 months post-diagnosis it is unclear if these changes persisted for these couples. However, studies on this phenomenon of ‘benefit-finding’ with women with breast cancer have been linked to improvements in their well-being long-term [52].

Rejecting and avoiding cancer

The adaptive processes that centred on the construction of cancer as a ‘blip’ seemed to support a general tendency to reject and avoid thoughts of cancer in the couple. These included protective withdrawal, avoiding sharing feelings or talking about cancer, resenting cancer, and diverging as a couple. Protective withdrawal was also called ‘under-burdening’ [36] or ‘protective buffering’ [25] and consisted of withholding feelings and withdrawing and distancing from each other [25, 30, 34, 36, 41]. Partly, this might have been a strategy to avoid burdening the other person, and to ‘be strong’ for the family, but most studies described it leading to a lack of emotional intimacy in the couple which could be isolating for both partners [25, 36]. As Fergus and Gray [36] emphasised, “*under-burdening* appeared to have more negative consequences for the relationship than did the more commonly voiced concern of *over-burdening*” (their emphasis, p.1317). However, it is perhaps worth interpreting the studies’ links between observed behaviour and couples’ adaptation with caution, given that not much is known of couples’ previous ways of interacting and their ‘normality’.

In another process related to this withdrawal, couples tended to avoid sharing their feelings and talk about the cancer, and especially fears about death it invoked [25, 30, 31, 34, 36, 39, 43]. This was apparent when couples denied any stresses caused by the disease in the interviews, even though they were present, as evidenced by their interviews as a whole [25]. Partly, this seemed motivated by a wish to protect oneself from distressing and intrusive thoughts, and partly by a desire to support the partner and remain ‘positive’. Staying ‘positive’ is often seen as an important mantra for cancer patients. Anecdotally ‘positive thinking’ is believed by many to positively affect health outcomes, although convincing research evidence of this link is missing [53] and pressure to ‘stay positive’ can induce guilt for despondent and fearful feelings. The rejection of the disease could translate into a rejection of the partner in a few cases [31, 41], a sense of feeling stuck [41] and difficulties in accepting dependence on the partner, which led to further distancing [36].

The final process in this cluster was that of ‘diverging’, which described a separation in the views of the disease and coping efforts of each partner in the couple [36, 38-41, 43]. A common time point for this separation was after the end of active treatment. One study described how during hormone treatment, with outward signs of the disease

diminishing, men wished to return to normal, whereas for women, taking hormones everyday was a reminder of ongoing treatment and that things were not ‘back to normal’ [41]. These ‘diverging’ views in some cases led to resentment and feelings of isolation. For some couples, diverging was a process present from the initial diagnosis onwards, and probably more indicative of a general way of relating between the couple, which they could not overcome with the additional stressor of cancer [43].

Overall, couples who saw cancer as a ‘blip’ or temporary digression had a wish to return to normal life as soon as possible. They attempted to minimise the impact of cancer, using avoidant strategies to protect themselves from the intrusion of the cancer, and did not seek transformation. Emotionally, avoidance of cancer perhaps helped these couples to hold onto the status quo, providing them with a sense of safety in a situation of uncertainty.

Normalising was commonly mentioned across both trajectories. A common process in cancer, it emphasises the wish to return to normal life before cancer. As discussed in both trajectories above, it could either contain the acknowledgment that this normal was a ‘new normal’ including transformations; or it could be related to a wish of returning to a situation exactly as it was (however realistic that may be). Most papers discussing normalising processes acknowledged that it can be such a ‘double-edged sword’, possibly signifying something positive and adaptive in some ways, and something maladaptive in others. For women, normalising processes were often an important anchor during treatment to hold onto something familiar that could contain their fears by keeping things normal for family and especially children [36, 39, 40]. In a similar vein, some men used normalising as a way of safeguarding against their own fears, and also to open up spaces for the women to focus on themselves without having to worry about the children [38]. However, when the return to normality was approached at a different pace or with different agendas for each partner within the couple, it could lead to diverging and conflict [35, 36, 40].

Accepting/ integrating	Rejecting/ avoiding
Supporting/caring (within couple)	Protective withdrawal
Sharing feelings	Avoiding (sharing feelings/ talking about cancer/death)
Accepting	Rejecting/ resenting
Growing together and meaning-making	Diverging
Normalising (double-edged sword)	

Table 6. Processes of adjusting to cancer

Discussion

This meta-ethnography is the first to synthesise qualitative studies on couples' experiences of breast cancer; highlighting how cancer and the couple were constructed in each study; and synthesising the topics, feelings and processes most pertinent for couples. Notably, cancer was almost always seen as a crisis initially, but then appraised in different ways, either as a gift or at least something with transformative powers; or as a 'blip' and one stressor amongst many. These ways of understanding cancer were linked to how couples understood and responded to the experience of having cancer as a whole. The way couples were constructed in itself was different across papers- they could either be seen as a dynamic and relational unit, where the whole was more than the sum of its parts and the couple had its own identity; or as two separate individuals with their own identities who stood in relation to each other, but were discussed quite separately. This conceptualisation of 'the couple' had implications for how research was approached and data were analysed, but this was rarely made explicit.

The main findings of this meta-ethnography in terms of topics and processes were that these were remarkably similar across studies, even though the studies spanned a period of more than 25 years and included couples of different ages, cultural backgrounds, and at different stages in their cancer experience in terms of time since diagnosis. The most pertinent topics were body image and sexuality; recurrence, uncertainty and death; and communication within the couple. Body image and recurrence are two topics which are also very commonly discussed in the breast cancer literature when only patients are included [28, 54-58]. This emphasises that although some of these difficulties might seem located in the individual women, they are in fact topics that are relational: negotiated and made sense of within the context of being in a couple. Examining these changes in a couple, rather than focusing only on the patient as an individual, can bring a more nuanced perspective, because it shows how change at a different pace for both partners, or a situation where one partner wants to change and the other does not, can bring new challenges to the couple. Adjustment in these cases is not only a process where an individual adjusts to a new situation; it requires the person to adapt to new ways of being with the person they are most familiar with, and to find new ways of defining behaviour in the couple. At this point, the couple may need help, for instance from a psychologically trained professional, to learn to express clearly their needs and expectations of each other. A systemic model may be particularly helpful here to guide intervention, because it allows an analysis of changed roles and supports the dynamic nature of relationships [6, 59]. This synthesis highlights that miscommunication can lead to the 'wrong' support being given, which in turn can lead to resentment, even though the best possible intent lay behind the actions. Disconnecting intent from the perceived effect of an action can

be difficult in couples at the best of times, and is even more challenging to negotiate when in the middle of a major crisis.

Couples also faced challenges with two of the most commonly highlighted topics in the included papers, death anxiety and sexuality. Both of these topics were highly emotionally charged, making them very difficult to discuss. This was particularly evident in studies where both partners had discussed them in their separate interviews, but not with each other. It is clear that health professionals such as breast care nurses would be in an ideal position to help facilitate these conversations and help couples share their concerns, to reduce their emotional isolation. Recent interventions designed to facilitate difficult communications for nursing staff have shown encouraging results in helping nurses feel more confident to discuss difficult topics [60] but additional resources would be required to make this idea a reality.

In terms of the feelings described as accompanying these topics there were few surprises, with participants feeling afraid, lonely and overwhelmed, but also angry, depressed, or, in case of the women, unattractive. The importance of this lies in some ways in the description itself. Overall, the description of feelings in the papers was not very rich, and some papers did not describe or mention feelings at all [37, 40] or very tangentially [25, 35] despite providing rich accounts of the experience overall. It is unclear why this was the case, but it might be connected to the requirements in published research to provide data for all inferences. Feelings by their very nature are more difficult to ‘prove’ and may rely on the descriptions of the researchers’ perceptions. They may therefore be considered too ‘woolly’ or ‘vague’ for the published paper stage, or even too ‘superficial’ [61]. Notably, where feelings were described, they were more often those of the male partners than the female patients. This refutes the stereotype that men are less connected to their feelings, and less emotionally expressive [62, 63], and provides much evidence that men need emotional support when their partners are diagnosed with breast cancer. Overall, it would be useful for papers to include more description of emotional experiences in detail, so that the emotional quality of the experiences is transferred in the publication, and so that support can be tailored more accurately.

One difference in study findings was related to cultural differences in participants, with a study on African American couples highlighting the important role that faith played in the couples’ adaptation process, and a study on Korean couples suggesting that different expectations on normative behaviour, and societal stereotypes led to different ways of behaving in the face of cancer. These rare examples emphasise the need to conduct more research into cultural differences in couples’ experiences in order to provide more culturally appropriate interventions.

Whilst topics and feelings were similar across the papers, two different types of processes could be synthesised from the articles. One process was clustered around accepting the disease and integrating it into the couple's life, and the other was clustered around rejecting the disease and avoiding it so that it did not intrude into the couple's life. That these two processes occurred in response to fairly similar emotional experiences lends credence to the idea that the appraisal of a situation defines adaptation to the situation, which is the tenet on which cognitive behavioural therapy is built [64]. However, it should also be noted that this appraisal is made from a particular position for each individual and couple, and individual and joint existing coping resources and other contextual factors need to also be taken into account. It was refreshing to see that the stereotypical construction of the male (mainly providing instrumental support, but not emotional support) was not replicated in the included studies. In most cases, men provided a lot of emotional support, and played an active part in the couples' relationship with each other and the cancer.

Because of this link to pre-existing and contextual factors, it is important to not label the different adaptational processes with a value-laden descriptor. Some papers in this synthesis seemed to suggest that the first process whereby couples integrate the cancer into their lives and see it as a transformative challenge might be a more adaptive or helpful process, and labelled the other process accordingly, as 'problematic' [43]. However, this was not a finding universally supported across papers. Overall, the finding was more nuanced, and seemed to hinge more on the congruence between each partner's interpretation. That is, if the cancer was viewed similarly by each partner in the couple, the couple coped better than if both had divergent views. This finding supports theories of couple adaptation to illness which have identified that apparently couples adapt better to illness if they construct it as a conjoint issue or "*our* problem" [46, his emphasis].

The limitations of this meta-ethnography to some extent reflect the limits of the included papers. Given the wealth of research literature on breast cancer, it is surprising how few qualitative papers exist on the impact of breast cancer on the couple relationship. Although the majority of participants included in these studies were affluent, White, middle-class couples (as in most other breast cancer studies), the sample was actually more diverse than anticipated, including studies on Korean [31, 33] and African American couples [34]. Time since diagnosis varied in the papers, and the analysis of pertinent topics, feelings and processes could not always be related to the timeline since this link was often not made explicit. However, the accounts provided in the papers contained rich descriptions and analyses of participants' experiences overall. This richness could not always be reflected in this meta-ethnography, because a synthesis by definition cannot provide as detailed an

analysis as the data it is based on. Nonetheless, it is hoped that this meta-ethnography provides a meaningful synthesis of the general topics, feelings and processes that are important to consider when thinking about couples' relationships and adaptation to a breast cancer diagnosis.

Clinical implications

When a woman is diagnosed with breast cancer, her male partner may experience a strange chasm between his experience at home and at the hospital. At home, male partners experience breast cancer diagnosis and treatment more often than not at the woman's side, and are placed in the centre of the storm. At the hospital, however, they are the periphery, on the outside looking in. This gulf is unnecessary and detrimental to the couple's adaptational process. As this meta-ethnography suggests, helping the woman to adapt means helping the couple to adapt. Health professionals working in oncology would be well-advised to include men much more in their considerations than is currently the case. This is especially true when sexuality and intimacy are discussed. Whilst this topic may make some health professionals feel embarrassed, the onus is on us as clinicians to start this conversation, because many patients will not. However, it is clear that the lack of inclusion of the care of the couple is in the vast majority of cases not a result of ignorance or obfuscation on the part of medical professionals, but rather, a direct result of inadequate funding and severe time and resource limitations. Therefore, equally, the health service would be well-advised to provide funding that is such that doctors and nurses have enough time to provide the couple with the care they deserve.

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Table 7. Summary table of included studies

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
Antoine et al., 2012	France	11 couples AGE: P ¹ : m=39 yrs, range= 27-51 yrs; H: m=40 yrs, range =30-58 yrs; Relationship length:m=12.81yrs, range 2-23 yrs; nr of children:2 couples =1, 3 couples=2, one each 3 and 5 TSD: m=3.3 yrs, range 1-8yrs	cancer centre; treating physician	phenomenology; dyadic perspective; undirected interviews, conducted separately; Interpretative phenomenological analysis	2 psychologists performed independent analyses	Body image (P); fear of recurrence (C); Uncertainty of future (C); new life/ more 'fundamental existence' (C); parenthood plans thrown into disarray, other options like adoption may need to be considered(C); stuck in seemingly never-ending ordeal of hormone therapy, resenting idea of normality (P)	Helpless /useless/ powerless (H); Anxious/ afraid/ fearful (P); Isolated/ lonely (P); Overwhelmed/ vulnerable (H); undesirable/ unattractive(P);	Caring/ supporting (within couple) (H); Protective withdrawal (P, C); Sharing feelings (within couple) (C); Normalising (H, C); Diverging (C); Growing together/ sharing (C); Rejecting/ resenting (P);
Chung &	Korea	7 couples	University	analysis following	translation	Fear of	Helpless	Caring/

¹ P=Patient, H=husband/partner, TSD=time since diagnosis

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
Hwang, 2012		AGE: Patients: median= 52 yrs; range: 33-60yrs; H: range 39-63 yrs; Relationship length: median = 26yrs; range 8-34 yrs; all couples had 2 children; TSD: 5-63mths	hospital breast clinic, Seoul; nurse introduction (of the approached, all participated)	Lewis and Deal (1995) semi-structured interviews of couple together in Korean, translated into English; inductive content analysis	triangulated between transcriber, translator and bilingual coder; back translation; analysis triangulated by coder and peer debriefer	recurrence (C); Communication (C); Uncertainty of future (C); changing sexual practices to support woman, but also struggling with changes (C); new life, benefit finding (C);	/useless/ powerless (H); Anxious/ afraid/ fearful (P, C); Isolated/ lonely (P); Angry/ frustrated(P); Depressed (C);	supporting (within couple)(H); Protective withdrawal (P, H); Accepting (C); Information gathering (C); Meaning-making (C);
Fergus & Gray, 2009	Canada	19 women, 11 spouses AGE: P: m = 53.5 yrs, range 37-66yrs; H: m = 50.5yrs,range 35-62 yrs Relationship length: for women m=24.7 yrs (range 7-40 yrs), for men: m= 25.7 yrs (7-38	postings at local cancer support organisations; international conference for BC patients	Grounded theory; interactional, dialectic understanding; Rolland's model of couple adaptation to chronic illness Dyadic coping; relationship vulnerability framework Focus groups/ semi-structured interviews, some multiple Joint/individual	second author reviewed emerging categorical scheme	Fear of recurrence (P); avoidance of difficult topics (H); communication difficult about certain topics like death (C); death and fear of future (P); uncertainty (C); lack of intimacy (C);	Helpless /useless/ powerless (H); Isolated/ lonely (P); Excluded (H); Overwhelmed/ vulnerable (P); Angry/frustrated (H);	Caring/ supporting (within couple) (H, C); Protective withdrawal (P, H, C); Avoiding thoughts/ talk of cancer/death (C); Normalising

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
		yrs); TSD: 2-12yrs		interviews		sexual disruption (C); instrumental support, emotional support (C); divergence – H push to return to normal, P resistant (C):		(P, H, C); Accepting (C); Rejecting/resenting (P);
Holmberg et al., 2001	USA	10 patients, 5 partners AGE: P: m=48 yrs, range 31-68yrs; H: m = 55, range = 33-70yrs; Relationship length: m= 26yrs,range 1-43 yrs; TSD: m= 47mths range=10mths- 6 yrs	university-affiliated oncology clinic, referred by treatment team	no theoretical framework directly referenced pilot study focus groups and individual interviews – same format used for interviews and focus groups to be consistent; content analysis	2 independent researchers analysed data and checked for inter-rater agreement; ‘excellent’ inter-rater agreement	core identity change- body changes led to feeling inadequate as woman/ partner (P); communication (C); fear of dying (P, H– not shared); importance of expressing affection in ways other than intercourse (P); reduced desire (P, H – not	Anxious/ afraid/ fearful (H); Isolated/ lonely(H); Depressed (P); undesirable/ unattractive(P); Avoiding thoughts/ talk of cancer/death (H);	Caring/ supporting (within couple)(P, H); Protective withdrawal (P, C); Avoiding thoughts/ talk of cancer/death (C);

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
						shared); Instrumental support provided by H (C); changes in friendship (P); concern about impact on children (C); some wives determined to keep normality – H felt sidelined(P,H);		
Kayser et al., 2007	USA	10 couples AGE: participants across 3 age groups: 35-45=3; 46-55 = 4; 56-65 = 3 age range 32-69 (M=50.9), relationship length: m= 24.3 yrs, range 2-42 yrs TSD: diagnosis within last 3	Via research study of Partners in Coping Program (PICP) - outpatients clinic at cancer institute and medical centre, New England	Bodenmann (systemic-transactional theory, Lazarus and Folkman's stress and coping theory Relational perspective, dyadic coping method of analysis: "listening guide" (Gilligan et al 2003)	Interviews were read by 3 co-authors; consistency and reliability checks between all co-authors; disagreements resolved by discussion	change in her body= loss for him (H, DA couple); authenticity (sharing feelings with partner, MR couples); uncertainty (DA couples); change in sex life (P, DA	Avoiding thoughts/ talk of cancer/death (H);	Caring/ supporting (within couple) (H, C); Protective withdrawal (C); Sharing feelings (within couple) (C); Avoiding thoughts/ talk of

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
		months All couples had children bar one (Lesbian, data excluded for this meta-synthesis)				couple); benefit-finding – strengthening of relationship (MR couples only);		cancer/death (C); Accepting (C); Rejecting/resenting (H);
Mak Wai Ming, 2002	Korea	83 women; 15/46 husbands all data for full sample: AGE: P: m=49 yrs, SD=5.58, range 35-60 yrs; H: m=53.07, SD=8.60, range=40-72 Relationship length: m=23 yrs, range= 1-41 yrs SD=8.36 TSD: 2mths - 21 years post-surgery (M=4.07 yrs);	via quant study; 86 patients recruited from surgical units at two hospitals; consent for women 100%; 53% for husbands	No theoretical framework mentioned; qualitative arm of mixed-methods study ; interviews were conducted separately; Categorisation/ coding scheme described;	analysed by 2 raters; inter-rater reliability of coding checked; interrater agreement 95-100%	Body image – but not as focused on loss of breasts directly, more related to what the husband thinks of her (P); physical discomfort (P, H); fear of recurrence (P); lack of communication/ understanding (P, H); fear of death and of health deterioration (P); loss of sexual desire	Helpless /useless/ powerless (H); Anxious/ afraid/ fearful (P, H) Fear of losing wife (H); Depressed (H); Avoiding thoughts/ talk of cancer/death (H);	Diverging (H); Rejecting/resenting(H);

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
						(P); sexual upset (P, H):		
Miller & Caughlin, 2013	USA	35 patients; 25 partners; <u>breast (13 patients)</u> AGE: P: m=51yrs, range=22-86yrs; H: 49 yrs, range= 25-71yrs; Relationship length: m=23yrs, range=2-61yrs; TS end of treatment: m=21mths, range= 4-60 mths;	Midwestern cities; purposive sampling: flyers, support groups, newspaper ads, university email announcement	rhetorical/ normative approach (Goldsmith, 2001,2004) interviews (separately); detailed audit trail; constant comparative method (Strauss+Corbin, 1990);	constant comparison; separate and joint coding; triangulation/ verification of analytical concepts	attractiveness (P); sexual relationship (C); uncertainties in relationship (C)	Helpless /useless/ powerless (H); undesirable/ unattractive (P);	Caring/ supporting (within couple) (H); later: having to give up caregiving (H); Sharing feelings (within couple) (C); altercasting – challenge (C);
Morgan et al., 2005	USA	12 African American couples AGE: P: m=52.58 yrs; H: 54.58 yrs; Relationship length: m= 24.75 yrs; nr of children: 2.83; children living in	large metropolitan area in mid-Atlantic USA; through support groups, churches, oncology clinics, and	grounded theory; semi-structured interviews of couples jointly; constant comparative method (Strauss+Corbin,1998);	subcategories and core categories were created and finalised through discussion by 4 research team members (triangulation)	body image – P struggled to accept changes, felt less attractive, but H did not find them less attractive (P); death (P); thoughts of death – H	Anxious/ afraid/ fearful (C); Overwhelmed/ vulnerable (C); Avoiding thoughts/ talk of cancer/death (H);	Caring/ supporting (within couple) (H, C); Protective withdrawal (C); Sharing feelings

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
		household: 0.92; TSD: 84% 6-36 months (17% <6 mths);	snowballing;			would avoid thinking about this (P); uncertainty (C); sexual relationship changed and was negotiated newly (C); life focus has changed (‘here and now’, living in peace) (C);		(within couple) (C); Accepting (C); Information gathering (C); Growing together/ sharing (C); Meaning-making (C);
Northouse, 1989	USA	50 couples AGE: P: m=50.4 yrs, range= 25-76 yrs; H: m=52.3 yrs, range= 27-78 yrs; TSD: 1-6 days post-mastectomy at 1 st interview, 2 nd interview 30 days later Relationship length: m=26.5yrs;	4 hospitals in southwestern Michigan;	Family systems theory; 2 phase descriptive research design; longitudinal study; separate tape-recorded interviews content analysis ‘time-oriented framework’	2 nurse researchers independently coded the data (triangulation)	loss of breast (P); appearance (body image); fear of recurrence (P,H); worry about future(P,H); fear of shortened life span, survival (P, H); uncertainty (P,H); worry		Caring/ supporting (within couple) (H); Normalising (P, C); Information gathering(P);

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
		range 2-53yrs				about seeing children grow up (P); normality;		
Picard et al., 2005	CAN (French)	16 couples AGE: P: m = 47 yrs; H: m =49 yrs; Relationship length: m: 16 yrs (±9 yrs); all couples had children, avg 1.8 TSD: 10-12mths	Oncology department University Hospital Quebec; 96 couples received invitation by letter, 16 respondents (16.7%)	Dynamic/developmental perspective; Relational/dynamic relationship process semi-structured interview of couple jointly Grounded theory (Strauss & Corbin 1990, Glaser and Strauss 1967) and post-validation scheme	Post-analysis validation process with subjects of study	personal crisis – physical changes (P); self-image – personal intimate relationship the woman maintains with herself (P); fear of recurrence (C); communication (C); uncertainty of future as couple(C); threat of death (C); voluntary decrease in desire to give P time to heal (H); intimacy +sexual	Helpless /useless/ powerless (H); Anxious/ afraid/ fearful (C); Overwhelmed/ vulnerable (C); Angry/frustrated (C); undesirable/ unattractive (P);	Caring/ supporting (within couple) (H); taking responsibility for own suffering and allowing the other a private experience (C); Sharing feelings (within couple) (C); Normalising (H, C); Accepting (P); Diverging (C); Information gathering (C

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
						relationship changes (C); existential growth experience (C);); Growing together/ sharing (C); Meaning-making (C)
Pistrang et al., 1997	UK	3 couples Mr+Mrs A: mid-30s, married 4 yrs; no children Mr+Mrs B: late 30s; married 14 yrs; 3 school-aged children; Mr+Mrs C: married 15yrs; teenage daughter; he mid50s; she late 40s TSD: 11-16mths	Recruited via survey study of psychological well-being and help-seeking in breast cancer from two London teaching hospitals	Goodman and Dooley 1976, 'help-intended communication' Tape-assisted recall 'Couples Helping Exercise' Data reduction procedure using 'analytic approach' (no further details)	Not mentioned	fear of recurrence (C); communication (C); life changes as a result of cancer(C)	Helpless /useless/ powerless (H); Excluded (H); Angry/frustrated (P);	Caring/ supporting (within couple) (H); Protective withdrawal (P); Sharing feelings (within couple) (H); Sharing feelings (in couple) (C); Avoiding talk of cancer/death (C); Normalising (P); Accepting (H); Diverging

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
								(C);
Shands et al., 2006	USA	29 couples Age: P: m=41 yrs, range 29-49 yrs; Length of relationship: m=15 yrs , range=3-24, Children at home: M=2 (range 0-3); TSD: 2-11 mths (m=5.7mths)	Via Family Home Visitation Programme (clinical trial); recruitment in Pacific Northwest city through clinics, physicians' offices, newspaper ads	'couple coached concern' content analysis using inductive coding method Krippendorff (1980), Spradley (1980) and Lewis and Deal (1995);	Quality monitoring checks: 2 independent coders unitised statements for all transcripts; categories were constructed through consensual agreements;	physical changes and difficulty to respond(C); fear of recurrence (C); communication (C); children-worry about impact (C)	Helpless /useless/ powerless (H); Anxious/ afraid/ fearful (C); Angry/frustrated (H); undesirable/ unattractive (P);	not knowing how to help her (H); Protective withdrawal (H); Information gathering (C); Growing together/ sharing (C); Meaning-making (C)
Skerrett, 1998	USA	20 couples AGE: 34-73; Length of marriage: 4 couples each had been married 1-12 years, 13-24 yrs, and over 37 yrs; 8 couples had been married 25-36 yrs TSD: 18-31mths	Part of larger study measuring individual distress, degree of relationship reciprocity , and marital adjustment; Letters to Y-Me (national BC support organisation)	Systemic perspective Phenomenological theory(Van Manen, 1990; Boss, Dahl, Kalan, 1996); Conjoint and individual interviews with everyone; Following grounded theory principles (Glaser&Strauss, 1967);	Quantitative data used to triangulate/ verify findings from interview data; outside rater was used to triangulate rating of interviews and global ratings of couple adjustment (97% inter-rater	body image (C); recurrence(C); communication (C); anticipatory losses and uncertainty of future (C); sexuality changes; Benefit finding; lifestyle changes –	Helpless /useless/ powerless (C); Anxious/ afraid/ fearful (P, C); Isolated/ lonely (C); Overwhelmed/ vulnerable (C); Angry/frustrated (C); Depressed (C);	Sharing feelings (within couple) (C); Avoiding thinking about cancer (P); Accepting (C); Diverging (C); Information gathering (C); Growing

Author	Country	Sample	Recruitment	Theoretical framework, method, analysis	Verification of data	Key Topics	Key Feelings	Key Processes
			and 2 oncology medical practices;		reliability)	‘living for the day’; ‘we’ attitude’; positive outlook (C)		together/ sharing (C);
Zunkel, 2002	USA	15 couples AGE: P: m=42.73, range= 29-51 yrs, H: m=43.9 yrs, range=30-54yrs; Relationship length: m= 17.6 yrs; Children: 9 couples=2; 5 couples=1; 1 couple=6; child age range: 1-20yrs, m=10.65 yrs; TSD m=4.7 mths (SD2.7mths)	From The Family Home Visitation Study (clinical trial);	Relational theory women’s development of self (Jordan et al 1991); Coyne & Smith, 1991) Carpenter & Scott, 1992: interpersonal model of coping Secondary analysis of data Analysis: Grounded Theory;	“Validity, reliability checks consisted of credibility, transferability, dependability,& confirmability according to established qualitative methodology.” →, not defined further	fear of recurrence (P); communication (C); impact on children (C); normalisation of household (C); Overwhelmed /vulnerable (P); Depressed (P);		Caring/ supporting (within couple) (H, C); encouraging her not to do too much (H, AP); Protective withdrawal (P); Sharing feelings (within couple) (C); Normalising (C); Diverging (C);

Table 8. Time since diagnosis diagram

Author	Months																			
	6	12	18	24	30	36	42	48	54	60	66	72	78	84	90	96	102	108	114	120+
Antoine et al 2012	1-8yrs																			
Chung & Hwang	5-63mths																			
Fergus & Gray 2009	2-12yrs																			
Holmberg et al 2001	10mths-6yrs		m=47mths																	
Kayser et al 2007	within last 3 mths																			
Mak Wai Ming 2002	2mths-21 yrs							m=4.7yrs												
Miller and Caughlin 2013			m=21mths																	
Morgan et al 2005																				
Northouse 1989																				
Picard et al 2005																				
Pistrang et al 1997																				
Shands et al 2006	m=5.7mths																			
Skerrett 1998																				
Zunkel 2002	m=4.7mths																			

Table 9. Example of synthesis step: extraction of items pertaining to ‘body image’ and ‘sexuality’

Topics	Patient ²	Husband	Couple
Societal construction of woman's body/ breasts =symbol of femininity; cultural differences, eg Chinese study nr 6 different Total: 10/14 papers	<u>8/14 papers: ‘physical changes/body image’</u> 1* ³ physical changes, withdrawal of the body, diminished self-esteem, questioning of femininity (P); 4 core identity change- changes of body led to feelings of inadequacy as woman and partner (P); 4 body image changes (P); 6 Body image – but not as focused on loss of breasts directly, more related to what the husband thinks of her (P); 7 attractiveness (P); 8 body image – P but H did not find her less attractive (P); 9 loss of breast (P); appearance (body image) 10 personal crisis: physical changes (P); self-image: relationship woman maintains with herself (P); menopause	6 loss of breasts = taboo, therefore not discussed or disclosed (H);	4/14 5 change in her body= loss for him (H, DA couple); 6 physical discomfort (P, H); body image/ altered body- not 12 knowing how to respond (C); 13 body image;
Sexuality Total: 9/14 papers	<u>2/14 Sexuality</u> 4 importance of expressing affection in ways other than intercourse (P); 6 loss of sexual desire (P);	10 voluntary decrease in desire to give P time to heal (H);	9/14 papers 2 changing sexual practices to support woman, but also struggling with changes (C); 3 lack of intimacy (C); 3 sexual disruption (C) 4 reduced desire (P, H – but not shared necessarily); 5 change in sex life (P, DA couple); 6 sexual upset (P, H); 7 sexual relationship (C); 8 sexual relationship changed, was negotiated newly (C) 10 intimacy +sexual relationship changes (C); 13 sexuality changes;

² The column refer to who in the paper the topic was most attributed to, that is, was it discussed as mainly an issue for the patient, or the husband, or the couple?

³ The numbers refer to the paper number in which it was mentioned; the papers were numbered in alphabetical order

CHAPTER II

Empirical Paper

Young Couples' Adaptation to Breast Cancer over Time: An Interpretative Phenomenological Analysis

Abstract

Introduction

This longitudinal qualitative study examines couple's adaptation to a breast cancer diagnosis over time.

Methods

16 interviews of four couples interviewed at two time points were analysed using Interpretative Phenomenological Analysis (IPA). The focus of the analysis was on those aspects of the adaptational process which were relational, i.e. negotiated between both partners in the couple. Particular attention was given to how those aspects changed over time.

Results

Changes over time were observed in three dimensions for the couple: 1) as external circumstances, or markers of the cancer trajectory (e.g. diagnosis, treatment, discharge) changed, couples' positioning in relation to the cancer changed; 2) metaphors used to give meaning to the experience had a bearing on couples' adaptation processes; 3) Sharing fears and couples' intimacy were closely connected and related to couples' adaptation to cancer and their altered circumstances. Men talked about the profound impact cancer had on them, contrary to existing stereotypes about men's lack of emotional expressiveness.

Discussion and conclusion

The experience of cancer is a relational phenomenon and ought to be addressed as such by Health Professionals. Metaphors and meaning-making are linked to couples' adaptation and could be explored in further depth to develop tailored interventions.

Introduction

Breast cancer is a disease that now affects almost 50,000 women per year in the UK [1]. Although improvements in treatment mean that the majority of patients live disease-free for many years, breast cancer remains a potentially life-threatening disease with psychological consequences that are now well documented [2-8]. Breast cancer affects a woman's relationship with herself on a number of levels, both physically and emotionally [9-14]. The existential threat that breast cancer poses mean a challenge that requires the woman to become acquainted with her own ways of being and relating to herself in new and daunting ways [15]. This differs for women across the lifespan, and raises distinct issues for younger, pre-menopausal women [16-21], such as reproductive concerns, balancing work and life, having a young family and/or less established partner relationships [22-24].

How women cope with the adjustment to breast cancer has been a major focus of psycho-oncological literature and practice. However, much of this literature has focused on women in isolation, and construed 'coping' or 'adjustment' as an intra-individual process [25]. Different perspectives on the topic, notably from clinical psychologists, have insisted that this rather narrow perspective negates the important role that a person's context plays in their emotional lifeworld [26-28]. In research, complex issues are often simplified to fit the research agenda, and traditionally psychology has particularly suffered from a gulf between academic researchers on the one hand and clinicians on the other. This has allowed the simplification of issues in research, and produced theoretically valuable but clinically less relevant findings; in turn furthering the gap between academia and clinic. Researching emotions and emotional adjustment is particularly complex and difficult [28]. And yet, starting with Northouse's seminal paper in 1989 [29], research has attempted to more adequately represent the clinical knowledge that a potentially life-threatening disease like breast cancer, with long and difficult treatments that alter a patient's life, is not experienced by women in isolation, as a simple physically-located entity.

Particular attention has been given to a woman's partner relationship, as the central relationship in her life (if she is partnered), and the one identified as the most important source of support [30, 31]. Research has indicated that the partner's ability to provide support is mediated by their own distress levels, and that partners suffer sometimes significant psychosocial consequences [32-34], and at times more distress than patients [35]. Importantly, this research points to the emotional interdependence of partners [31], meaning that one person's vulnerabilities effect the emotional stability and adjustment of the other [36-38]. Several factors have been identified as mediating psychological adjustment, such as marital satisfaction, external support systems, or the degree of uncertainty experienced [8, 28, 38].

A number of models have been developed to define these coping processes, ultimately with the aims of predicting what facilitates good adjustment; of identifying couples at risk of struggling with adjustment; and of developing interventions which can help couples adjust better [28]. Common to these models, such as inter-personal coping [39], relationship-focused coping [40], dyadic coping [41] or the relationship intimacy model [28] is the belief that closeness of the relationship is an important predictor of overall adjustment, and that the impact of cancer needs to be examined at the level of the *couple relationship*, not the level of the individual. Further to these models, theories underlying specific therapeutic approaches such as systemic family therapy, which emphasise the relational nature of human emotion, have also been used. A systemic perspective is useful because it stipulates that as human beings, we are all part of social systems and cannot be viewed meaningfully in isolation [42].

Qualitative literature on the topic is scarce, but can add an important dimension by examining couple interaction in more nuanced detail than is possible with quantitative approaches. The previous chapter has summarised the adaptation processes that couples commonly engaged in, and found that these can be synthesised across studies into two main trajectories: an 'accepting/ integrating' trajectory which consisted of four processes, namely caring within couple, sharing feelings, accepting and growing together/ meaning-making; and a 'Rejecting/ avoiding' trajectory, which consisted of the four processes of protective withdrawal, avoiding each other in the couple, or the diagnosis or both, rejecting/ resenting the diagnosis, and diverging from each other in the couple [43]. Although evidence is limited, some studies seemed to suggest that the latter trajectory has some negative consequences for couples' adjustment [41, 44], whereas the 'accepting/ integrating' trajectory facilitated open communication and seemed to have beneficial consequences both for the woman's and the couple's adjustment to cancer [28, 41, 43, 44]. Although as the previous chapter concluded, it may be the case that congruence between both partners' approaches in the couple may be more important to good adjustment than their overall strategy.

However, the idea of a 'trajectory' already points to the important aspect that this experience develops over time. It is well known that adjustment to breast cancer is a long-term [45] dynamic and fluid process with phase-related patterns [29, 38, 46], changing over time [47]. As Charmaz [15] has emphasised, this is an active and engaging meaning-making process, in which couples have to "repeatedly rethink how they live and who they are becoming" [15]. And yet, almost all research to date has been limited to one timepoint, providing only a snapshot of a couple's experience. Reducing this complex process to a rigid template of interaction might be a result of temporal and financial restrictions, but ultimately reduces the value of such research for clinical application.

The present study can be seen as a starting point to explore the dynamic interaction of couples over time when diagnosed with breast cancer. It used Interpretative Phenomenological Analysis (IPA) as its method of analysis to allow the in-depth exploration of the participants' lifeworld and relationships from their perspective [48]. IPA is grounded in a long phenomenological and hermeneutic tradition which emphasises the importance of understanding the meaning a person gives to an experience, without the constraint of pre-formed notions or theoretical concepts which limit the analyst's perspective. The starting point of the 'double hermeneutic' process (making sense of a person making sense) is the person's own reference point, which allows a more flexible analysis [48]. This stance is arguably naturally compatible with a clinical psychologist's way of understanding their client's world, and therefore particularly useful in the context of the current study. Systemic theory principles also informed the analytical stance. Some principles of systemic theory are particularly useful for the analytic process. For example, it emphasises the importance of viewing different perspectives simultaneously [49] and suggests that change in one part of the system affects change in the whole of the system, highlighting the dynamic nature of the adaptive process [50].

Aims

This study focused on young pre-menopausal women specifically to narrow its focus, as a group with potentially less established relationships⁴. The primary aim was to understand how each partner in the couple and the couple together related to and coped with the experience of cancer; and how this adaptation process changed over time. Furthermore, male partners of women with breast cancer are often not given the chance to express their own experiences, in research or clinical practice. We wanted to rectify this and understand more about their specific ways of coming to terms with this situation. Knowing from clinical experience that the meaning of having cancer can dramatically change over time, we included a longitudinal element in the study with the aim to capture some of these changes.

⁴ One aim had also been to specifically examine pre-menopausal women's experiences of interrupted family planning, but due to recruitment difficulties this aim could not be realised.

Methods

Participants

This study purposively recruited a homogenous sample of White British heterosexual couples. Couples were eligible if the woman in the couple had been diagnosed with early breast cancer within 12 months prior to their participation in the study, if she was pre-menopausal before the cancer diagnosis, aged between 18 and 50, and if both partners in the couple were willing to participate. Early breast cancer was defined as any stage cancer but excluding those with recurrent, metastatic or terminal diagnoses. Both partners in the couple needed to be able to be interviewed in English to be included.

Four couples participated. The women's age ranged from 33-43 (mean= 40) at the time of interview one. The male partners' average age was 44 (range= 41 – 48). All but one couple were married, and all were cohabiting. Relationship length ranged between 6 and 23 years (mean= 13.5 years). All couples had at least one child, aged 2 to 26. One couple had one joint child, and the male partner had two further children from a previous relationship. One couple had no joint children, but the woman had two children from a previous relationship. Joint income ranged from 35K to 75K (mean = 55K), and highest educational achievement ranged from A-levels (high school) to degrees. All participants were employed at the time of interview one, with two women being on long-term sick leave due to cancer treatment (for further participant details see Table 1 in the appendix). The aim was to interview couples as soon as possible after the patient's diagnosis, but in practice this was difficult to achieve due to practical considerations and gatekeeping practices. The length of time elapsed between diagnosis and first interview was between 76 and 273 days (mean= 168). (For a timeline see Table 2 in the appendix).

Procedure

The study protocol was reviewed by independent reviewers at the University of Birmingham. Ethical approval for the study was granted by the University of Birmingham Ethics Committee and a NHS Research Ethics Committee (13/WM/0034, for approval letters see Appendix 3). Participants were recruited in two breast cancer treatment centres in the UK: one in the West Midlands and one in the Southwest. Recruitment at both centres was via treating physicians and breast care nurses in order to afford participants maximum anonymity before consent to participation. Eligible women attending a clinic for treatment were given written information about the study by the clinician and asked to either contact the study researchers or consent to have their contact details passed on to the study team. Three couples who were

Young Couples' Adaptation to Breast Cancer over Time: An Interpretative Phenomenological Analysis approached declined participation, two because the women did not want to discuss it with their husbands, and one because they thought their level of English would be insufficient.

After an expression of interest, couples were telephoned or met in person by the study researcher and given the opportunity to discuss the study in further detail. If they consented, a convenient time and location for the first interview were arranged. All but one couple chose to be interviewed at their treatment centre; one couple was interviewed at home. Interviews were conducted between August 2013 and April 2014. At the end of the first interview it was agreed that the study researcher would contact the couple within 4-6 months for a follow-up interview. The timeframe was determined by maximum possible time lapse between interviews one and two, given the overall study timeframe. The maximum possible time lapse was preferred to capture as much of the adjustment process and to go beyond initial treatment stages, if possible. Interview two was conducted between four and five months after interview one (mean time lapse = 145 days). All but one couple chose to have interview two at home, with one couple preferring the treatment centre. Each partner in the couple was interviewed separately by the same researcher. Couples were interviewed separately in order to allow each partner to express their own experience of being in the relationship and dealing with cancer, and to identify possible divergences, differences and commonalities. Whilst this approach contains an acknowledged paradox of an awareness of the importance of the couple relationship within the experience of cancer, and yet a focus on the individual account, we felt that if there were divergences they would be more easily identified in separate interviews [51]. We were also keen to provide partners with the opportunity to talk about things they may not have disclosed in the partner relationship [52].

Participants filled in a written consent form at each interview, and were also asked basic demographic information at interview one. The interviews were recorded using a digital recorder. Each participant was given a £10 high street voucher at the end of each interview as a token of appreciation for participation. The first interviews lasted between 30 and 74 minutes (mean=43 minutes) and the second interviews lasted between 36 and 68 minutes (mean=46 minutes).

The aim of the study was to recruit between four and five couples. This number was decided on the basis of a suggestion by experienced IPA researchers that a study conducted for a professional doctorate might contain between 4 and 10 interviews (not participants) [48]. Smith et al. warn that it is more problematic to meet IPA's requirements of in-depth data analysis with too many participants, than with too few. Nonetheless, it was decided for this study to aim for four couples in total, in case participants withdraw and do not participate in the second interview.

Analysis

All 16 interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis procedures following Smith et al. [48]. Qualitative data analysis software (NVivo) was used to facilitate the coding and help organise the complexity of the analysis [53]. The analysis procedure was adapted to focus on the longitudinal element of the study as follows: the starting point was the first interview of the patient (time 1) of the couple. The interview was read and re-read and the recording listened to. Initial coding was 'broad-brush' and focused on identifying the main themes, 'story' and 'feel' of the interview with regard to the individual experience, but also with a focus on what might be considered part of a relational experience, for example roles, feelings, main concerns and worries. Linguistic, conceptual and descriptive ideas were noted, as were emerging connections and relations between these ideas. As a next step, the partner's interview at the same time point was coded similarly. Then, both interviews were read together to identify similarities and differences across the couple, e.g. how the couples related to each other, and what their 'stories' were. Next, the interviews at time point 2 were explored, again starting with the patient's and moving on to the partner's. Those were compared and contrasted with each other, too. Finally, each person's interviews were read together across both time points, to look for changes and similarities over time. At this point, the focus was on those themes which were connected to the couple's relational experience, guided by questions of 'what aspects of the experience relate to the couple's way of relating to each other? What influences their relationship with each other?' A matrix was then filled in for each couple detailing these themes, and important changes and similarities over time, and a summary of each couple's 'story' across time was developed. Then the analysis moved to the next couple. When all transcripts had been coded the matrices across couples were compared for similarities and differences in relating to these themes over time, to develop the overarching 'story' of the findings presented here.

Results

Couple vignettes

Although the study was focused on couples, both for space reasons and reasons of confidentiality and anonymity, it was decided not to provide a detailed analysis of each individual couple's adaptation process over time. However, to give a flavour of the intricate detail of this process a brief description of each couple, and their way of dealing with the adjustment to cancer over time will be given as well as a discussion of the overall

Young Couples' Adaptation to Breast Cancer over Time: An Interpretative Phenomenological Analysis navigational journey (see Appendix 1 for descriptions). These vignettes formed an important part of the analytic process in the sense that they are the result of reflection on the process of the interviews with each partner, and the information gleaned both from the participants' stories and from a clinical experience of 'being in the room' with them. Whilst these interviews were conducted as a researcher and not in my capacity as a clinician, they are nonetheless influenced by my own sense-making process as both a researcher and a clinician.

Findings

Together with the focus on couple adaptation and not individual adaptation to cancer, the longitudinal aspect of this study is its important focus. This adds a not insubstantial level of complexity to the doing and presentation of the analysis. The complexity is in part related to the fact that change over time is important at different intersecting levels. In this paper, I will focus on change at three important levels: One, changes occurring in external circumstances: these are mainly time points in the cancer trajectory, and relevant external markers, such as diagnosis, end of active treatment or discharge; two, changes occurring in meaning over time and relevant emotions and behaviours related to those; and three, changes occurring in the way couples relate to each other.

Changes in external circumstances: The treatment trajectory

The interviews spanned three potentially important milestones of cancer treatment, diagnosis, end of active treatment, and discharge. Each of these milestones was marked by particular concerns coming to the fore for couples.

Diagnosis was described by all couples as a huge shock and utterly overwhelming:

"We found out on the Wednesday or something, and it took me till the Sunday or Monday before I stopped just feeling completely covered in it" (Mark, Int1⁵)

Accompanied by a feeling of vulnerability, and an existential threat inherent in the cancer as a potentially life-threatening disease:

"I think it just makes you realise how vulnerable you are and how fragile things are, or can be." (Olivia, Int1)

Going through treatment, couples described a sense of adaptation and settling into a routine dictated by hospital procedures, especially chemotherapy, with its frequent visits and particular pattern of subsequent 'good' and 'bad' days:

⁵ Int1 denotes interview 1, Int2 denotes interview 2.

“Then the chemo started the end of January, for six sessions every three weeks, which was, I found that it was, the three weeks, it followed a pattern, the first week I was quite unwell, the second week I was much better and able to go out and about a little bit, and then the third week I was pretty much back to normal, but obviously back to appointments and coming back for the chemo at the end of that week”

(Olivia, Int1)

At time two, two couples had reached the end of active treatment and one couple had been discharged. The men in the sample seemed to describe end of active treatment and discharge in similar terms, as a joyous time that promised an end to the presence of cancer in their lives:

“Above and beyond everything else you’re just ecstatic and happy that the worst of it is hopefully over and you can move on with things” (David, Int2)

For the women, the picture was slightly more nuanced. End of active treatment was generally celebrated, especially the end of chemotherapy. As Gina put it, “you start feeling more human again” (Int. 2). But the women seemed more apprehensive about the discharge. Given the different trajectories that the couples in this study were on, only one woman had already been discharged, with the others still having to navigate this milestone. Olivia, who had been discharged, felt that a safety net of frequent hospital visits was lost:

“They’ve finished what they gotta do, they’ll check me regularly and there’s the support there and everything if I need it, ahem so it’s almost as if that’s it, done, dusted, made better, finis[...], which is good really. Feel a bit apprehensive at times thinking oh my goodness I’d, I’d rather just be coming to the hospital, because if there’s anything wrong, then you’d find, you’d find out for me.” (Olivia, Int2)

Approaching discharge, the women seemed to feel lingering uncertainties and were fearful of a recurrence – which had not even featured for women earlier in the treatment trajectory when the cancer threat itself was still so overwhelming. Fear of recurrence signified a move beyond the immediate threat, to anxiety over a potential future threat. When asked directly, the men rejected the idea that they dwelt on a potential recurrence of the cancer on a day-to-day basis and insisted it was ‘at the back’ of their minds.

For most couples, the differences in adjustment for both partners were small and easily accommodated. However, the example of one couple where for a short time a bigger

Young Couples' Adaptation to Breast Cancer over Time: An Interpretative Phenomenological Analysis

difference between his and her pace of adjustment was visible suggested how this might lead to resentment:

“I think once they gave me the all clear-ish as they can give, for the cancer, he did go through a patch of oh well, you're better now, get on with it, ahem stop dwelling on it and stop being a martyr to it all. And I was a bit like since when was I a martyr to it? But it's also not gone away, you know [...] it could come back at any point, [...] you can't say oh well, you're better, let's get on with life and forget it ever happened” (Lucy, Int2)

Whilst certainly not wanting to pretend that this had never happened, most women insisted that a sense of 'normality' had returned and now prevailed. They acknowledged that some upheaval in life was normal, especially with children. This might suggest both that cancer had been integrated in to their life course and also that they rejected the idea of cancer having had an overwhelming influence:

“It's hard because our normality from before was different anyway because obviously with [younger daughter] and her growing up and so things are different, but whether they would have still been as they are now if things hadn't happened the way they have now if that makes sense, I, I don't know.” (Helen, Int2)

At the second interview, most couples engaged in some discussion of the future in ways they had not done at time one. Having a future outlook at all seemed to indicate a move beyond the initial phase of adjustment to cancer, because that initial phase was dominated by a focus on day-to-day functioning and “taking each day as it comes” (Gina, Int1). The type of future goals couples had were remarkably similar. All couples spoke of wanting to have the holiday they have had to postpone due to their cancer diagnosis in the previous year:

“We got our holiday booked for next September that's the one we were supposed to have gone on this September we'd postponed that until next September so that's all booked and I'm looking forward to that” (Gina, Int2)

It is possible that this holiday might have meant more than just a well-earned period of recuperation after a stressful year. It might signify an end of a very difficult period, having come full-circle, and an attempt to re-establish normality. Another very common change was related to priorities in life, prioritising enjoyment over financial gain, and the wish to spend more time with the family:

“So we’re trying to kind of do the things that, you know, we’ve missed out on, and do more stuff with [son] together now, so you know, those are good things, those are positive things that have come out of it” (Lucy, Int2)

Although some participants also highlighted how difficult it was to maintain this change in the face of mundane pressures:

“Day-to-day you end up just getting dragged back into it, especially with work you just, it just, you kind of just go back to your normal routine because you can’t help but get drawn back into it, ahem yeah [laughs]” (Helen, Int2)

Against this backdrop of adjustment to different treatment phases, couples used different metaphors and meanings to make sense of their cancer diagnosis, which in turn affected the way they dealt with it.

Changes in meaning - metaphors used by couples to describe their relationship with cancer

Metaphors in medical discourse in general and cancer specifically can be powerful tools to help patients bring familiar understanding into a chaotic new and uncertain world of terminologies and jargon [54]. Initial research into metaphors of cancer has identified a number of different ones, such as cancer as ‘challenge’, ‘punishment’ or ‘enemy’ and considered these to be more or less adaptive in terms of the person’s coping processes [55]. Little research has examined to date how these metaphors are used within couples. The metaphors used to make sense of cancer in this sample were fairly homogenous. After an initial understanding of cancer as an existential crisis and huge overwhelming shock that was common across all participants, two main metaphors were discussed in relation to positioning oneself and the cancer: ‘the battle’ and ‘the bubble’.

The ‘battle’ against cancer

The battle metaphor is one of the most long-standing and dominant metaphors in public discourses of breast cancer [56-58]. Three couples used this metaphor and described cancer as something to ‘fight’ or ‘beat’, with both partners in the couple aligning and ‘fighting’ it ‘side by side’:

Again, because I think, you know, being exposed to this because of [friend], he just went into action-mode, just right, we’re gonna, we’re gonna beat this, we’re going to fight this, you just, you know, you tell me what you need and we’ll just do it” (Helen, Int1)

Constructing cancer as something to 'fight' externalised the threat and moved it from something overwhelming and engulfing to something external that could be seen, grasped and attacked. It made the threat more manageable and gave couples a shared focus or "shared cause" as David called it:

"It's really quite sort of cliché to say the cancer's brought us closer together, but I think that's obvious that it does bring you closer together, because you're both fighting the same cause" (David, Int 1)

Over time, this process led to participants rejecting the idea that cancer had an overwhelming influence on them, which was particularly evident at the second interview. Here, David alluded to a common cancer narrative of triumph over cancer, and simultaneously rejected that story for them; thereby avoiding further attributing cancer a strong hold on their life:

"But I genuinely don't think a lot else has changed, we are still who we are, we don't go around with big placards or stickers saying, you know, we had cancer and we won" (David, Int2)

Some research has pointed out that the 'battle metaphor' can be problematic in cases of advanced disease where the battle is not 'won' and where patients can experience guilt and responsibility for the disease and not fighting hard enough [54, 59, 60]. However, in this context of early breast cancer this was not as problematic. It has also been pointed out that this metaphor is "inherently masculine, power-based, paternalistic, and violent" [54] and might therefore be objected to by some patients. Whilst beyond the scope of this study, a more nuanced future study could ascertain if there is a gendered preference for metaphors for couples where the woman was diagnosed with breast cancer.

The 'bubble'

More unusually, a different metaphor was used by one couple: Mike described cancer as a 'bubble' –and Lucy, his wife, in a similar vein used the idea of 'bubble wrap'. This image, especially of the 'bubble', suggest a degree of remaining overwhelmed by anxiety at the time, not externalising the cancer, but describing it as something engulfing. At time 1, both partners described it as only around Lucy:

"It's just the way of you kind of putting this bubble wrap around you and just going OK, well I can function, you know, ahem, but I am protecting myself at the same time" (Lucy, Int1)

“It’s like [...] she’s in this bubble all the time, that’s how, that’s how I’ve felt, that’s how I’ve felt, looking in and there’s nothing I can do, nothing at all [...] she’s in that bubble, and I feel like I can’t get to her” (Mike, Int1)

Being in a bubble might have seemed protecting to her, but also meant a separation between the two partners, as well as being paralysing for him – there was nothing he felt he could do, the action orientation was not clear, as it would be with a battle metaphor. At time 2 Mike’s description encapsulated both partners, which indicated that some shift had taken place:

“It was like looking outside of a bubble. Nothing matters out there, that bubble, it’s all what’s in there. You know what I mean? It’s in that bubble. We, we put a bubble all over our lives, if you know what I mean” (Mike, Int2)

The metaphors used to conceptualise cancer seemed to have bearing on individual’s emotional reactions. This is possibly most evident when comparing the cases of two men who suffered panic attacks as a result of the cancer diagnosis. Mark described his panic attacks as becoming more intense and frequent as cancer treatment intensity lessened:

“I’ve had a few more sort of panic days I think but I don’t know why [laughs] erm, cos it’s been mainly positive news all the time. it’s normally times when I’m on me own[...] it’d just creep up on me, and it was like ‘shit, what happens if she goes?’ pardon me French, and it’s just running through, the thought of losing her, and stuff like that, it absolutely scares the heebie-jeebies out of me” (Mark, Int2)

Mark was surprised that his ‘panic days’ were more frequent even though he was receiving good news about the cancer. He and his partner had made strong use of the ‘battle’ metaphor. Initially at the intense treatment stage, Mark was very heavily involved, monitoring tablet use and accompanying his partner to all appointments. Now that treatment intensity has lessened, and there is less demand on ‘action’ (which is emphasised by the ‘battle’ metaphor) maybe Mark has had more time to reflect on the potential impact of the disease and felt more overwhelmed by it.

The case was different for Mike, who also suffered from panic attacks. Mike had described how at time 1 his panic attacks were very frequent, even though he had never suffered from them before. Mike used the ‘bubble’ metaphor to describe his cancer experience. At the second interview, he described how his panic attacks had ceased as soon as his wife was given the ‘all clear’:

“Since the chemo and all the medication from that side, as soon as we got all over that, and as soon as we heard that it had got rid of the cancer, I, I’ve had no panic attacks, I’ve had, I’ve not been stressed out, I’ve not been worried about nothing”
(Mike, Int2)

Thinking about his metaphor, and the bubble as something overwhelming, one can surmise how cancer may have paralysed Mike to a point where he could almost not breathe (literally), and as soon as it was lifted (by the all-clear message) his worry disappeared. It stands to reason to see the panic attacks of these men as an emotional outlet for fears which could or would not be said out loud. Suppressed consciously, they may have manifested as a physical attack. It is important to note that for some men, the interview was the first time they spoke in depth about their emotional experiences (which for one man brought on another panic attack).

Changes in the relationship

Talking about emotions: your ‘deepest, darkest fears’

The emotional fall-out of cancer is huge and complex. Here, one crucial part of the emotional landscape of cancer will be discussed, which was particularly intimately linked with couple relations: fears. The fears accompanying a cancer diagnosis tap into the most profound fears any human being can encounter, the threat to one’s very own existence (for patients), or that of a loved one (for partners). In fact, fear and cancer in public discourse are often conflated [56]. In these circumstances, some things become almost unsayable, because as humans we have the irrational thought that what we say out aloud becomes true- when the perverse paradox is that the reverse is true, that speaking out can reduce your fears. In relation to cancer a number of ‘unsayables’ exist. It possibly still holds true for the older population of Britain that the word ‘cancer’ itself may be unsayable, and referred to instead as ‘the big C’ or in one case in this study with a completely different name: ‘Henry’ by the father of one participant at interview one. Other than this case, the ‘unsayables’ in this study were largely related more to fears, thoughts about fears and death than the cancer itself. About half of the participants avoided naming their fears directly and spell them out, instead using approximations such as ‘worst case scenario’ or ‘the worst’ as in the following sentence where Mark does not complete the sentence:

“you do fear the worst, and I’ve sat there thinking crikey, what happens if she’s, you know, if it is the worst” (Mark, Int1)

When ruminating about their fears, and presumably thinking about death, participants tended to use phrases also used to describe depressive thoughts, such as 'black thoughts' or 'deepest darkest fears'.

Three participants discussed the content of these existential fears in the interview, even at the first interview. Interestingly, in two of the three cases the participants talked about their partner's fears, not their own:

"And so I said to him, I said if you're frightened that I'm going to die just say it out loud" (Lucy, Int1)

"There's an obvious fear for [wife], isn't there, there's been obvious fears that, you know, she, she could ultimately die, and we've been honest about that, and she's had, she's had meltdowns over that, more to do with the kids than anything else [...] had his prom last summer, and she was convinced that she wasn't going to be here for the other two's, that was difficult, that was one of her fears, but that, that's all-encompassing with the fear of dying I guess" (David, Int1)

Only one participant directly spelt out her own fears:

"So before my operation, before we knew exactly what was going to happen, we talked about... well I talked about, and he told me not to be stupid, what happens if, you know, something happens, what happens if, you know, it's more serious when they take stuff away, what happens if in two years' time I pass away, will you make sure you look after the girls." (Helen, Int1)

This is noteworthy because these examples illustrate that even saying your own fears out loud is extremely difficult, and something not everyone can manage, especially not when they are still reeling from the initial shock. It is also worth to note that no gender difference was evident in the data with regards to being able to express fears.

Changes over time in the way that fears and death were discussed were noticeable. Of the five participants who had not discussed their fears at time 1, or not spelt them out, three discussed their fears more openly at time 2, and could name them directly. As an example, Mike who called it 'the worst' in the extract above, in the second interview says the following:

"When the worst case scenarios come back in your head and you start thinking well what would I do, and then, well, it kind of goes through this initially where it's like this scary imagined life without her here, and then it's like you just see all horrible

because she wouldn't get to see everybody, she wouldn't see her kids grow older and her grandkids grow up, and then it's the grandkids would miss out on the nan growing up, and then the kids obviously as well, cos the kids lost their dad last year, erm, and then it, and then it'll be like, oh crap I wouldn't be growing old with her" (Mike, Int2)

Whilst this change in disclosure might be related to a number of factors, it could be that increased distance from the initial shock, and an increased sense of control as well as the promise of a good outcome facilitated participants to feel more able to voice their fears. And yet, a number of participants disclosed that they could not or would not talk about their fears with their partners, largely because they did not want to upset them. Conceiving of their emotions as a 'burden', they did not want to add to their partner's load:

"I've probably been shying away from it actually, because obviously, I don't want to, I don't want [wife] to feel more emotional or more pressure than she is now" (Mike, Int1)

Perhaps, in some cases, not wanting to discuss fears may have also been related to particular feelings of anxiety that this conjured up, since anxiety often has avoidance as its behavioural component. Whilst this may not be problematic per se, the anxiety-avoidance cycle tends to support an increase in anxiety [61, 62], which may explain, for instance, the men's panic attacks in this sample.

Looking at the couple dimension, in two couples both partners had a similar approach to sharing their feelings, and in two couples the partners' approaches differed. However, the participants did not seem to think that this caused them substantial difficulties or led to ruptures in their intimacy, although the woman in one of these couples was keen for them to access external support in order to be able to discuss their feelings. Of the four couples, only one emphasised that they had been very open with each other and their children from the beginning, and talked about what may happen, shared their fears and vulnerabilities. And yet, most participants talked about the potential benefits of talking, and even considered it in some ways protective:

"I think it's such an enormous thing, that actually bottling it forever is going to make you lose your marbles if I'm honest, you know" (Lucy, Int1)

This was maybe precisely why participants valued the research interviews: as a way of discussing their fears with an external person, who they could share their emotions with

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without having to censor themselves or feel responsible for that person's emotional well-being in the way they perhaps would with their partner. Linking this back to the 'battle' metaphor described earlier, in relation to communication about fears the metaphor is maybe a two-edged sword. On the one hand, it might give people a way of dealing with their fears and 'dark thoughts', as the following extract illustrates, where Gina used it to defy her thoughts and change them to 'fighting talk':

"What's the point of me thinking about it now? Because it may not happen? And that's so, if I do start, then I think more sort of 'no, I'm not gonna think that way' because it's not gonna beat me" (Gina, Int2)

But one cannot help but wonder what the consequences might be if the outcome were not as positive as it was in her case- might the person end up blaming themselves? This is alluded to also in the following extract, where David seems to tentatively make a causal link between their policy of being open about the cancer, and Olivia's survival:

"I guess if [wife] hadn't have been here and we hadn't, we weren't sitting here now when, if I'd have been sat here now a widower, we could have turned around and said you handled it the wrong way, but because she's gone through it and she's come out the other end fighting, I can turn around and say we handled it the right way" (David, Int2)

Coupled with the superstitious belief of some that saying the worst case scenario out loud may increase the likelihood of it happening, one wonders whether different communication styles could lead to a sense of betrayal within any relationship- something which would need to be carefully discussed with any couple. As it was, the couples in this study largely reported that sharing their fears brought them closer together:

"I've probably always been the stronger one out of the two of us, and so having to rely, or be, you know, have [husband] for my support has made a big difference, and it's probably made him open up more to me than he has done in the past, he had to show a little bit of emotion as we were going through everything we were. So ahem yeah, I think we're probably more honest with each other" (Helen, Int1)

This process continued throughout the trajectory, and by the second interview, most couples discussed that they no longer talked as much as they had before, but that the process of

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growing together had continued, and resulted in greater closeness. One husband described this as a process of mutual growth and faith in each other:

“You go from being a single person to being sort of sum of parts, ah, and that’s where you get the strength from. And when you’re looking to fight something like this, that is pretty much everything, we have faith in each other, we have faith in what each other does, we don’t have faith in any religion, we just have faith in ourselves really, and that makes us stronger” (David, Int2)

Intimacy was of huge importance for all couples, and for all couples not only bound up with verbally sharing vulnerabilities, but also with their sexual relationship.

Intimacy and sex

Sexual intercourse, or being sexually intimate, had been disrupted temporarily for all couples. Intimacy was created and maintained in many other ways. For some couples, lack of sexual intercourse had been ‘a minor blip’ and they resumed their sex life quite quickly:

“It’s had a knock-on effect, especially over the first [...] six months really [...] circumstances just dictated otherwise, illness, tiredness, whatever, and yeah, it did, the lack of it I think did frustrate us both [...] it’s changed again now, so that’s good, so we’re back being intimate with each other, we have a, we have a good physical relationship now, so yeah, it was just a minor blip if you like” (David, Int1)

For others it took longer, and they created intimacy by cuddling or holding hands as Gina said:

“We’re intimate, we hold hands, a cuddle on the settee and that, yeah, cuddle up in bed, but that’s as far as it seems to go... at the moment” (Gina, Int1)

But, as Mark, her partner, described it,

“A lot of the time anyway, it’s not just about doing the deed so to speak” (Mark, Int2).

In all cases, the lack of sexual intercourse was a consequence of how the women felt, both physically (e.g. tired, exhausted) as a result of the treatments, and also psychologically, in terms of their comfort with their altered bodies. Helen described at time 1 how she was not ready to let her husband see her naked:

“I don’t want to take my bra off, and, I know he wouldn’t care [...] Ahem, but yeah, I mean things are slowly getting back to normal, but it has taken a while, and I, and that’s me, not him [...] just don’t feel like a proper woman with, you know, one boob, I suppose” (Helen, Int1)

But by time two, she had made that leap:

“I think I just became a bit braver and thought I can’t keep covering myself up [...] [husband] had always said from day one, you know, [...] ‘doesn’t bother me at all’ but I just wasn’t ready. But probably within the last three or four months ahem it’s been, and I don’t know what’s changed, I just ahem [laughs] got a bit braver” (Helen, Int2)

In all cases, the men insisted that that their attitude towards their wives, and their attraction, had not changed:

“Since she started the chemo, she started to lose her hair and things like that, I had not, I still love my wife from the day I first met her, I’ve got no change in that at all, I love my wife to bits, she may lose her hair, she may lose her eyebrows and her eyelashes and things like that, and her nails, still, I still love her to bits” (Mike, Int2)

Passing time made a crucial difference to the adaptation process in relation to intimacy, facilitating a process where the women got more used to their altered bodies and slowly returned to having sexual relation with their partners (which in turn might further facilitate body confidence). However, it cannot be emphasised enough that sexual intercourse should not be seen as the only means to create intimacy. Intimacy was more important for all couples than sexual intercourse. Some women discussed feeling sorry for their partners, and wondered if they somehow felt pressure, but again, all men insisted that they understood the situation and were not seeing sex as a priority. Furthermore, it is important to highlight that a phase of disrupted sexual intercourse, but not intimacy, was normal for all couples in the sample, and indeed is common for the majority of couples undergoing treatment for breast cancer [28, 63].

Discussion

This is the first longitudinal qualitative study exploring young couples’ experiences with breast cancer. The aim of this study was to explore how a diagnosis of cancer can alter and shape a couple’s ways of relating to each other over time; what impact this may have on the

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support they can give to each other; and how this is related to their ability to integrate and cope with the cancer diagnosis and treatment. In particular, the study demonstrated how couples create meaning out of the experience of having cancer, and how this meaning-making process in turn has consequences for the couple's overall adjustment.

The experiences across the four couples and across time showed several similarities as well as some important differences. The 'story' of each couple unfolded over time, alongside an external structure or scaffold, which was created by the external markers of diagnosis and treatment, which shaped the cancer experience. Universally, the cancer diagnosis was experienced as a shock initially. Subsequently, all couples also experienced some sort of resolution of their situation, given that they had all received a diagnosis of early breast cancer with no further complications.

In term of main findings, changes over time shaped couples' experiences in three important ways. One, the passing of time and the moving along the cancer trajectory with its milestones (such as diagnosis or discharge) had a key influence on couple's adaptation. Near diagnosis, the cancer seemed utterly overwhelming, whereas at the time of discharge a future-orientated concern in the shape of fear of recurrence took over. Positive aspects were fairly absent at time one, but for couples further along the trajectory ideas about changes in life priorities provided a way to see some positive aspects of their experience.

Two, the meaning couples ascribed to the cancer coloured the way in which they felt and behaved when passing along this trajectory. A battle metaphor, common in cancer, seemed particularly helpful because it helped couples to externalise the threat and align in the fight against it. Although the potential danger of this metaphor has been highlighted in advanced disease, where patients can feel they haven't fought hard enough [59, 60], in this case of early breast cancer the metaphor seemed very helpful. I would agree with Luker [60] that in some cases (of early disease), the metaphor could be suggested as a helpful coping aid and that asking couples what meaning they attribute to cancer and identifying their metaphors may help to tailor psychosocial support interventions.

Three, how couples related to each other against the backdrop of these external changes in order to cope with the challenge the cancer provided, changed over time. Fears about cancer and death, and the communication about it in the couple, were a major challenge. Previous literature on communication patterns in relationships when people are diagnosed with cancer has highlighted that communication seems to follow different patterns; some people want to avoid talking about the illness and not deal with it and others want to discuss and directly confront it [49, 64]. Whilst the literature tends to suggest that disclosure leads to better adjustment than non-disclosure overall, there is also some suggestion that

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conflict occurs in couples with conflicting communication styles in the couple, that is, one partner wants to discuss it and the other does not, and that this is more important than the actual communication style [64]. In this study, this finding has not been supported. Two of the couples had differing communication or disclosure preferences, especially with regard to their fears, but this per se did not seem related to any relationship difficulties as far as one could ascertain from the interviews. Furthermore, in this study, contrary to gender stereotypes, men talked openly and movingly about the devastating emotional impact of the disease on them – but crucially with the researcher, not necessarily with their partners. As a result, some of the women perceived their husband as not 'being emotional', even though two of the four men were having panic attacks. Not only does this highlight how useful individual interviews as opposed to joint ones had been, to allow the men to tell their own 'story'. It also demonstrates how gender stereotypes and gendered roles in the relationship can be a hurdle for open communication, something that clinicians ought to be sensitive to, especially when their own assumptions and stereotypes come into play. Men tended to become more focused on their own experience in the second interview, when recovery for their partners was advanced. This highlights the importance of a longitudinal study because previous studies with one time point have found that men talk more about their wives and appraise the stress they experience as indirect [41]. Intimacy and sexuality changed over time and were crucially important in facilitating couples' closeness with each other. Whilst all couples experienced some disruption to their sex life, they were intimate in other ways, and sexual relations were restored after some time had passed. Generally, women's feelings about their altered bodies were the reason for a temporary absence of sex in the relationship.

Using the broad-brush interpretation used by the first chapter [43] the couples' adjustment processes in this study could be mapped on to the two trajectories, the 'accepting/integrating' trajectory, and the 'rejecting/avoiding' trajectory identified. Couples one, three and four could be classified as following the 'accepting/integrating' pathway, whereas couple two could be classified more as following the rejecting/avoiding trajectory. However, looking at the results in detail, arguably most couples utilised elements of both, to varying degrees. For example, couple three overall aligned with each other and accepted the cancer diagnosis, integrating it into their lives, but they also rejected the idea of it having too much of an impact. Hence the research presented in this study lends further credence to that model, and also provides some more nuanced findings.

Understanding both the wider classification of adjustment processes, and the detailed ways in which these are played out in individual couples is important for a more nuanced understanding of how couples cope with a diagnosis of cancer. It helps health care

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professionals in situations of care to avoid giving out simplistic messages of hope and reminds us of the complexities of the situation for each couple. This study of the couples' processes also demonstrates the importance of understanding couple's adjustment to cancer over time. Had I only interviewed couples once, the understanding of their adjustment over time would have been much more limited. Dependent on the time point of the interview, it would also have provided a much more skewed understanding of the couple's experiences, because it can then only provide a snapshot of an experience of one particular moment in time. This study, by contrast, has allowed the exploration of adjustment as a more dynamic process. Encouragingly, it also showed adjustment as a process that for these four couples ended in relative emotional equilibrium or contentment. This may just be a result of the selection process, and couples who struggled more may have chosen not to partake. However, couple two chose to participate precisely because both partners struggled and welcomed the opportunity to discuss their experiences in depth with a neutral professional, so the selection process may not be entirely to blame. It is notable that several participants commented directly on the benefit of taking part in the interview, describing the cathartic and therapeutic effect of talking about their feelings openly. It has been highlighted that a good research interview can have such beneficial effects [52], which provides further support for the idea that all couples diagnosed with cancer may benefit from brief informal psychological interventions, or at least a good conversation with nurses skilled in discussing difficult emotions and allowing time and a safe space for these to be explored.

Limitations

The study was limited to four couples. Given time constraints, this small sample size was necessary to not make the detailed analysis unmanageable. In order to allow some comparison across couples, inclusion criteria were narrow to create a more homogenous sample. For example, only White British heterosexual couples were included, and it is likely that the experiences of couples of different configuration, for example, with a different cultural background or same-sex couples could vary widely. Although this study aimed to recruit younger couples with the aim of discussing less established relationships, this aim could not be achieved, due to difficulties recruiting a sufficient number of couples. The relationships in this study ranged from 6 to 23 years and can therefore not be described as 'less established'. Due to time and space restrictions the dynamics of each couple could not be presented in enough detail to do the process justice. However, it is hoped that the compressed vignette can be seen as a template for the actual complexity of the participants' lives. Ideally, a longitudinal study would accompany couples from the moment of diagnosis for at least two

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years, beyond their discharge to capture more changes over time. However, practically, recruiting close to diagnosis posed a significant challenge for us, and following a couple over a longer time period was not possible within the time frame of this study.

Conclusion

Women diagnosed with breast cancer do not exist in a vacuum. Adjustment to the breast cancer diagnosis takes place in the context of the woman's relationship. The meanings and metaphors that couples use to make sense of the cancer, the ways in which they can share their fears, and how they negotiate intimacy and sexuality are all related to how well the couple adapt overall. Couples may benefit from supportive care which addresses those areas.

Clinical Implications

Support to facilitate adjustment to a cancer diagnosis should not only be given to individual women, but it should be considered that interventions may be more effective and more valued when given to couples as well, or in some cases instead of to the patient alone. When considering support interventions for couples, it is important to acknowledge the wider trajectories that couples can follow, but also focus on the specific partnership and changes over time. Asking couples what meaning they attribute to cancer and identifying their metaphors may help to tailor psychosocial support interventions. Therapeutically, metaphors can be a powerful tool, and can help couples align in their sense-making process. Stereotypes of male emotional expressiveness can hinder adequate supportive care to be sought or given, and health care professionals might benefit from observing their own 'blind spots' in this area to not inadvertently miss a need. Conversations about difficult topics may not be started by the couple, and health care professionals might be called upon to discuss fear or sexuality to help the couple communicate about these issues. However, fulfilling this role means the professionals themselves might benefit from training and adequate time in their role to provide this care. As a health care professional, being open, flexible, and curious about the couple facilitates the ability to provide the best support.

Reflections

Breast cancer is a difficult and emotionally challenging area to conduct research in. Before I embarked on the Clinical Psychology training I spent 8 years of my work life as a PhD researcher and then as a Research Fellow working in the field. Speaking to participants about such difficult subjects as sexuality, death and their innermost fears, a sense of humility at their

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openness has never left me. In addition, being engaged in thinking about these topics is, of course, personally challenging. It has meant that I have spent maybe more time thinking about my own attitude to my own death and potential illness than many of my peers.

Interestingly, I have also detected a difference in the way in which I conducted and thought about the interviews for this thesis, when compared to previous work I conducted as a researcher. Although I completed this piece of work with my 'research hat' on, I am now also a clinician. I have gained a new language and new knowledge and tools for understanding the complexities and intricacies of human behaviour. Things have become even more multi-faceted. At times, this has been a real bonus, because it meant I could interpret my data using both academic and clinical knowledge. Before my clinical training, I might not have been so attuned to couple's relationships with each other, and I certainly would not have known how to conceptualise panic attacks, never mind to help someone overcome them mid-interview! But at times, my 'dual identity' has also been a challenge. It has meant I felt sometimes trapped on the border between those areas, unsure if I could use my clinical interpretations meaningfully in an academic context, or if they would be regarded as 'anecdotal' or trivial. For example, I had strong reactions to the presence of each participant in the room with me during the interview, and this presence and how I interpreted our encounter (how they seemed to me and how I thought they might have 'used' me) contributed to my sense-making of the participant's position and account. At times, I would have liked to make this more explicit, but from an academic perspective shied away from it because I had no quotes or data to 'prove' my points. In some ways, this dilemma maybe highlights the particular skills clinicians can bring to research – but also suggests that in academia more efforts need to be made to understand the relevance of these nuanced and clinically derived observations as valid contributions.

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Appendix 1. Couple Vignettes.

Couple 1: Gina & Mark⁶

Gina and Mark have been together for 6 years. Gina has two grown-up children from a previous marriage, and small grandchildren. Gina and Mark were first interviewed three months after diagnosis, and then four months later. At the first interview, Gina was undergoing chemotherapy. At time 2, she had undergone a first operation, with a second one scheduled, after which radiotherapy would commence.

At time 1, the couple's routine was determined by chemotherapy. Mark had taken on a variety of supportive roles. They both seemed comfortable with their roles, and aligned their efforts to "beat" the cancer. Gina presented as a private person who initially tried to keep her feelings to herself for fear of upsetting others. Mark acknowledged that the emotional impact on him as a result of the existential threat that cancer represented had been enormous. Although the couple had some communication about their fears, he also kept some to himself to protect her. The couple maintained intimacy in a number of ways but had no sexual intercourse.

At time 2, the routine of treatment had become normality, and overcoming the cancer was becoming more of a reality. Their sexual relationship was not "fully back", but both also said that being intimate in other ways was just as important to them. Gina stressed that she had learned through the experience that she could fully rely on her partner, which in turn facilitated greater openness and intimacy in the couple. Mark spent more time discussing the emotional impact on him than previously, which might have been facilitated by Gina's recovery.

Overall, the couple seem to have embraced cancer as a learning experience, seeing positives in terms of the impact on their relationship. They talked of short- and longer term goals, including going on the holiday they missed because of her diagnosis, changing jobs and spending more time with the family.

Couple 2: Lucy & Mike

Lucy and Mike have been together for 15 years. They have a small child, and Mike has children from a previous relationship. They have had IVF and had eggs frozen which they destroyed after the cancer diagnosis. Lucy and Mike were interviewed six months after the

⁶ All names used in the study are pseudonyms and all identifying characteristics have been removed as much as possible to preserve participants' anonymity.

Young Couples' Adaptation to Breast Cancer over Time: An Interpretative Phenomenological Analysis

diagnosis, when Lucy had had chemotherapy. At time two, five months later, Lucy had had bilateral mastectomy plus reconstruction, and did not need additional therapy.

At time 1, the existential threat that the cancer represented to the couple seemed to almost overwhelm them. Mike was having panic attacks. They did not talk to each other about their anxieties for fear of hurting the other. Both felt distant and isolated. Since the diagnosis, Lucy seemed to long for a role reversal where she could be the more passive patient and have Mike take care of her. He appeared to not know what to do, feeling helpless. This process was accompanied by feelings of resentment and further withdrawal on Lucy's part, as a self-protecting mechanism.

By time two, Mike's anxiety had apparently dissipated completely because of the hospital's 'all-clear' message, which meant his fear of losing her had not materialised. Lucy talked about feeling resentful of him for returning to normality too quickly, but also of being relieved because now his focus could be more on her. Her anxiety, distress and resentment seemed to have reduced. Mike retold their experience in the last few months as them both having been in 'the bubble', moving from exclusion to inclusion. The couple could focus on some positives and future planning, mentioning holidays and re-decorating their home, as well as spending more time as a family.

Metaphorically speaking, the couple's gravitational centre seemed to be located closer to Lucy, rather than in the middle between the two: when Lucy was not feeling well, the system suffered, but with her recuperation, the system also recovered.

Couple 3: Olivia & David

Olivia and David have been together for 23 years. They have three children. They were first interviewed nine months after the diagnosis, when Olivia had had chemotherapy and lumpectomy, and was mid-way through radiotherapy. The second interview was 4.5 months later, when Olivia had been discharged from hospital care.

David and Olivia presented as dealing with the cancer together and openly. At interview one, they seemed no longer completely overwhelmed by the cancer. Olivia did not extensively talk about the emotional impact of the disease, but highlighted her vulnerability. David also downplayed any emotional impact but acknowledged the existential threat that cancer represented. David saw his role as that of a supporting partner, and both discussed that as a couple, although already close, they had gotten closer by sharing vulnerabilities, and by 'fighting' a common goal. The couple described a good sexual relationship which created intimacy, and which had only briefly been disrupted during chemotherapy, a 'minor blip'.

At time 2, Olivia had been discharged from hospital care. Her recent return to work was for them a marker of 'normality'. David rejected the idea of cancer still being a part of their lives, even in the form of fear of recurrence, whereas for Olivia, some uncertainties lingered. This seemed to be related to her discharge from hospital follow-up, which had been like a safety net for her. David commented on the 'brutality' of the discharge proceedings as a sudden abandonment. He also acknowledged the cancer's potential power for disruption more than at time 1, possibly facilitated by Olivia's recovery. Both discussed their relationship as not having changed dramatically, and both throughout the interview resisted attributing cancer as having a strong hold on their life.

Looking into the future, Olivia felt that whilst making the most of life was important, it was also easy to slip back into old habits. She discussed a change of priorities in terms of spending more time with the family. David commented specifically on how helpful it had been for both of them to participate in the interviews, using them therapeutically.

Couple 4: Helen & Robert

Robert and Helen have been together for 10 years and have two small children. Their first interview took place four months after the diagnosis. Helen had had a mastectomy and was contemplating reconstruction. The second interview was six months later. Helen had postponed her reconstruction.

Even at the time of interview 1, the cancer experience was discussed as in the past. Both had a strong wish to 'return to normality'. Overall, the couple seemed comfortable with the way they related to each other and the support they provided for each other. The couple talked about cancer having made them closer by forcing them to open up more. They discussed their fears only to a limited extent. The couple had not resumed their sex life to the same extent as before, which both attributed to Helen's feelings about her changed body. At interview 1, Helen was already talking about a change in outlook, mainly related to an increased focus on her immediate family.

At time 2, Helen had postponed her reconstruction, feeling ambivalent about it. It seemed to serve as a reminder of the cancer and promise a return to bodily 'normality' at the same time. 'Normality' in terms of family life had returned for them, but Helen also emphasised that with their children growing up, normality was changing constantly anyway. She described having become more comfortable with her body and sexual relations were restored between them. Helen acknowledged that thoughts of recurrence were present for her, and influenced by thoughts of her friend who died of breast cancer. For Robert, feelings of recurrence seemed less present. Both partners talked about having changed their outlook on

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life with a focus on enjoyment over financial gain, and more time spent with the family, although Helen also acknowledged that it was easy to get sucked back into old routines.

Table 1. Couple demographics

Couple	Age of the patient	Age of the partner	Relationship length (year)	No. of Children	Disease ⁷	Treatment ⁸	Time since diagnosis, interview 1 (days)	Time since diagnosis, interview 2
1	43	41	6	0 joint; 2 hers	Grade 3, ER+, HER2+	CT, Lumpectomy, HT	76	204
2	38	48	15	1	Grade 3, ER-, HER2-	CT, bilateral mastectomy, RT, reconstruction	190	339
3	42	43	23	3	Grade 2, ER+, PR+, HER2-	CT, lumpectomy, RT, HT	273	396
4	33	44	10	2	Grade 2, ER+ Her2-	Mastectomy, reconstruction, HT (not taken)	131	292

⁷ ER=oestrogen receptor; HER= Human epidermal growth factor2 receptor; PR= progesterone receptor

⁸ CT=chemotherapy; RT=radiotherapy; HT= hormone therapy

Table 2. Couple timeline

	timeline																			
	2012		2013											2014						
	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr			
Couple 1						F01 diagnosis			Interview 1				Interview 2	Interview 2						
Couple 2			F02 diagnosis							Interview 1				Interview 2						
Couple 3	F03 diagnosis									Interview 2				Interview 2						
Couple 4							F04 diagnosis				Interview 1						Interview 2			

CHAPTER III

Public Dissemination Document

Introduction

More than 50,000 women in the UK are diagnosed with breast cancer every year [1]. Advances in treatments have considerably improved survival, and in the vast majority of cases breast cancer is no longer a death sentence. Even so, being diagnosed with breast cancer remains a frightening event. The disease itself with its life-threatening potential can mean an existential crisis for patients. And the treatments, such as surgery or chemotherapy, often have severe side effects, which may temporarily substantially lower the quality of life of patients. This heady mix of difficult-to-bear treatments and an existential crisis mean that a breast cancer diagnosis can have sometimes severe psychological consequences [2-6]. Fortunately, research also demonstrates that this psychological upheaval is often short-lived [7, 8].

Somewhat surprisingly, much of the psychological literature has focused on women in isolation, even though we know full well that meaning-making is a dynamic process that does not occur in isolation, but in exchange with a person's lifeworld [9-11]. However, relational research is more complex and time-consuming, and maybe less common as a result. Nonetheless, more complex psychological theories of the process of adaptation to cancer have recently been developed [12]. These have, for example, been based on systemic theory, which focuses on relations between different stakeholders (i.e. people) within any system (i.e. a relationship) [13, 14]. Most crucial in this situation are women's closest relationships, and especially her partner relationship (if she has one).

Other research has used the coping theory developed by Lazarus and Folkman [15, 16] as a starting point, and highlighted that there is a clear relationship between patients' and their partners' adjustment to the disease [17-19]. Researchers using those ideas have also coined phrases like 'dyadic coping' to highlight that coping is a relational activity, negotiated between partners in a relationship. Adjustment to a breast cancer diagnosis can be difficult for both partners in a couple and challenge their way of being, both independently and with each other. For example, couples' roles and responsibilities can be challenged as a result of a cancer diagnosis; and this can provide a challenge for the couple's relationship and their intimacy [20-25], leading to some couples coming closer together and others moving apart [11, 26].

One difficulty with the extant research has been that it has often focused on each partner's individual coping response and then linked the two, rather than seeing coping as a completely relational activity, which cannot easily be separated into its individual components [10, 11]. Furthermore, cancer in this literature is often described as 'something that happens to the couple', when a relationship can also be important resource for couples [11]. In this context, cancer can also be seen as "an opportunity to forge a more intimate bond" (ibid.).

This thesis focuses on couples' experiences of breast cancer and aims to explore and synthesise the extant literature on the topic, as well as present findings from an empirical qualitative longitudinal study.

Literature Review

Chapter I reviews the empirical qualitative literature on the subject of heterosexual couples' experiences when the woman has been diagnosed with breast cancer. A systematic literature search provided fourteen papers, published in the English language between 1955 and April 2014. The literature was synthesised to provide a meta-ethnography following steps suggested by Noblit and Hare [27]. The focus of the synthesis was on the main topics, feelings and processes that were of concern to couples diagnosed with breast cancer. The synthesis also aimed to place these in a wider context of how 'cancer' and 'the couple' were constructed or understood.

The meta-ethnography described that how cancer was understood ('constructions' of cancer) changed over time: after an initial very common perception of cancer as an existential crisis, two main trajectories of adapting to cancer could be identified. One defined by an integration of cancer into the couple's life, and one which had avoidance and rejection of the diagnosis as its key features. How these two trajectories are linked to how well couples adapt to a cancer diagnosis overall remains questionable. Couples were variably seen as two separate individuals or as a dyad, which had consequences for how data was analysed. The three most important topics highlighted for couples were 1) body image and sexuality, 2) fear of recurrence, uncertainty and death, and 3) communication within the couple. These were accompanied by feelings of helplessness, fear and anger for the men, and vulnerability, loneliness, and unattractiveness for the women. Both parties also felt overwhelmed and depressed at times. Men expressed a variety of emotions openly, contrary to stereotypes seeing them as less emotionally expressive.

The literature review resulted in a number of recommendations for clinical practice. For example, it suggested that women's partners should be more integrated into the care provided at the hospital. This is especially important when sexuality and intimacy are discussed. Whilst this topic may embarrass some health professionals, the onus is on us as clinicians to start this conversation, because many patients will not. However, it is clear that the lack of inclusion of the care of the couple is in the vast majority of cases not a result of ignorance or obfuscation on the part of medical professionals, but rather, a direct result of inadequate funding and severe time and resource limitations. Therefore, equally, the health

service would be well-advised to provide funding that is such that doctors and nurses have enough time to provide the couple with the care they deserve.

Empirical Paper

Following on from the literature review, Chapter II presents the findings of a longitudinal qualitative study which examined the experiences of young couples when diagnosed with breast cancer, over time. Four couples, recruited from two large cancer centres in England, took part in two separate interviews. The first interview took place as soon as possible after diagnosis, and the second approximately six months later. The purpose of the study was to understand in more detail than previously known how each partner in a couple and the couple together related to and coped with the experience of cancer. Knowing from clinical experience that the meaning of having cancer can dramatically change over time, a longitudinal element was included in the study with the aim to capture some of these changes.

Interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis, with a procedure adapted to allow the analysis of linked couple interviews [28].

To summarise findings, changes over time were observed in three dimensions for the couple: 1) As external circumstances, or markers of the cancer trajectory (e.g. diagnosis, treatment, discharge) changed, couples' positioning in relation to the cancer changed. After the initial shock of the diagnosis, couples got used to the routine of cancer treatments, with discharge being another milestone that was more difficult to navigate emotionally. 2) Metaphors used to give meaning to the experience had a bearing on couples' adaptation processes. Couples in this study used two different metaphors: a very commonly used 'battle' metaphor, and a less commonly known 'bubble' metaphor. It was observed that the 'battle' metaphor, i.e. seeing cancer as something external that the couple could fight, was useful because it allowed couples to externalise the threat of cancer and unite against it. It might be a useful therapeutic tool, especially when the breast cancer prognosis is good, such as for women in this study. 3) In terms of relational aspects changing over time, talking about their fears with each other, and couples' intimacy and sexuality were closely connected and related to couples' adaptation to cancer and their altered circumstances. Men talked about the profound impact cancer had on them, contrary to existing stereotypes about men's lack of emotional expressiveness.

Using the broad-brush interpretation used by the first chapter [43] the couples' adjustment processes in this study could be mapped on to the two trajectories, the 'accepting/integrating' trajectory, and the 'rejecting/avoiding' trajectory identified. Couples

one, three and four could be classified as following the ‘accepting/integrating’ pathway, whereas couple two could be classified more as following the rejecting/avoiding trajectory. However, looking at the results in detail, arguably most couples utilised elements of both, to varying degrees. For example, couple three overall aligned with each other and accepted cancer diagnosis, integrating it into their lives, but they also rejected the idea of it having too much of an impact. Hence the research presented in this study lends further credence to that model, and also provides some more nuanced findings.

Overall, this study has allowed the exploration of adjustment to a breast cancer diagnosis as a dynamic process, showing in some detail how couples have negotiated this experience over time. Encouragingly, it also showed that adjustment for these four couples ended in relative emotional equilibrium or contentment.

In terms of clinical implications, this study emphasised that the experience of cancer is a relational phenomenon and ought to be addressed as such by Health Professionals. Metaphors and meaning-making are linked to couples’ adaptation and could be explored in further depth to develop tailored interventions.

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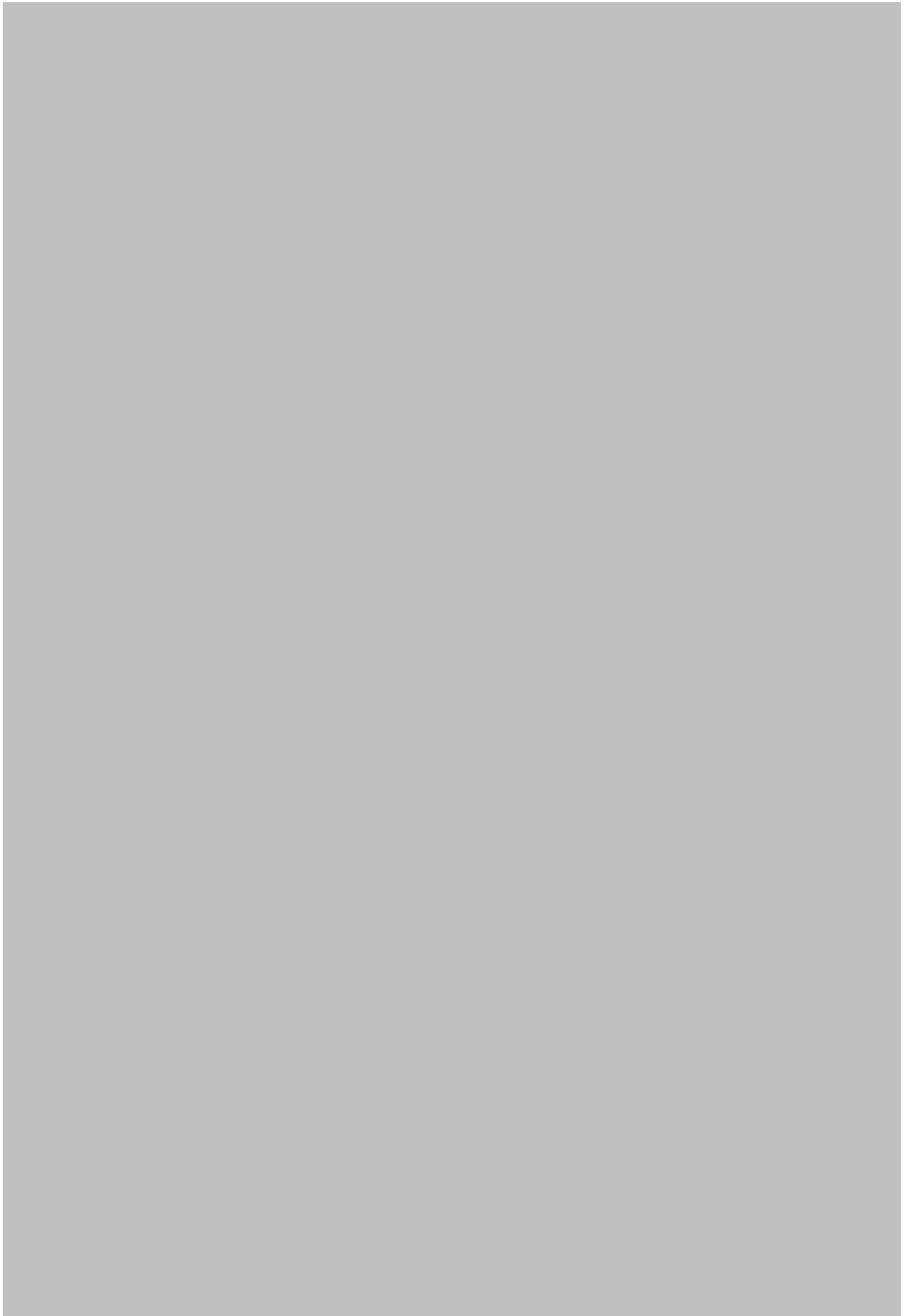
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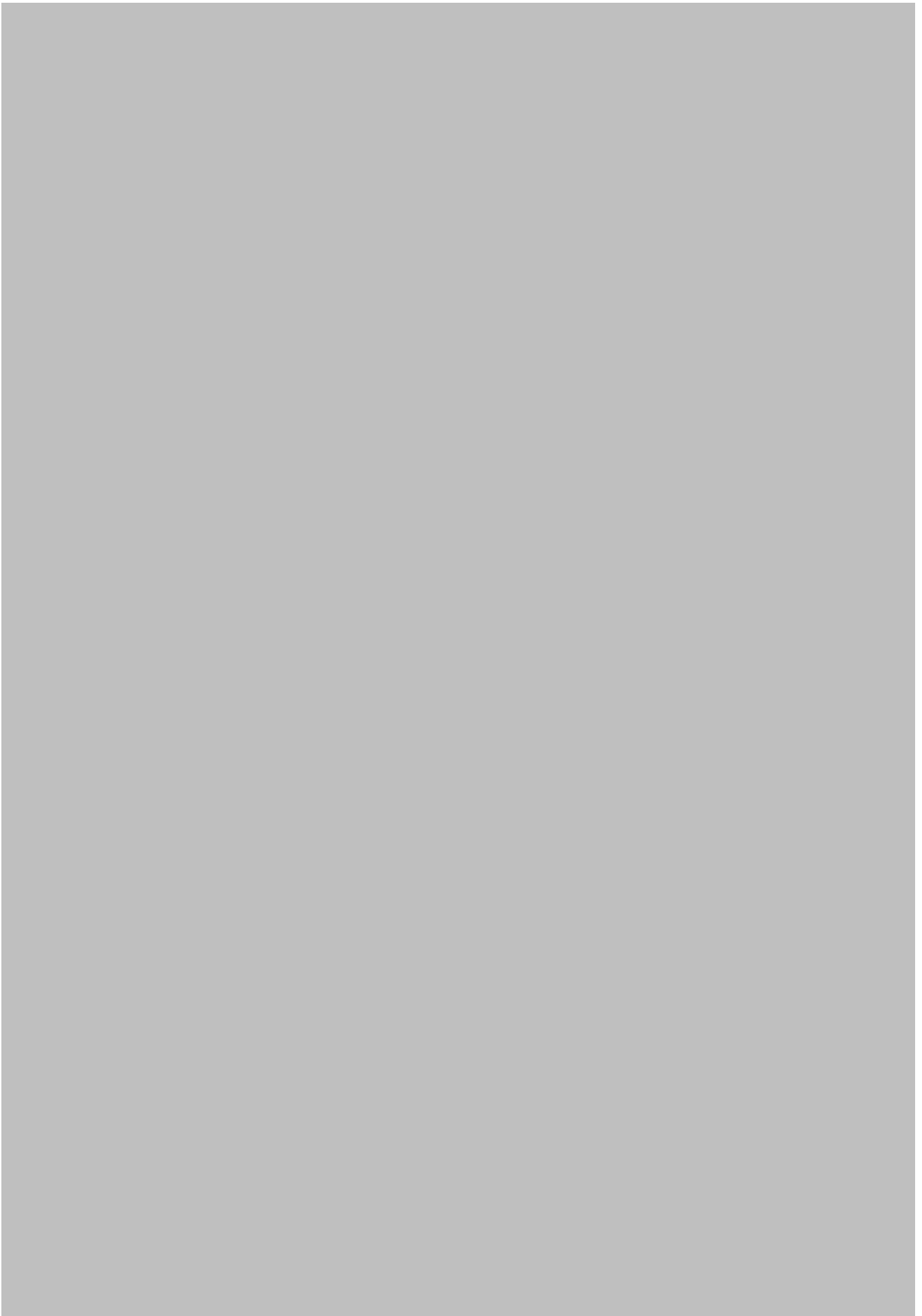
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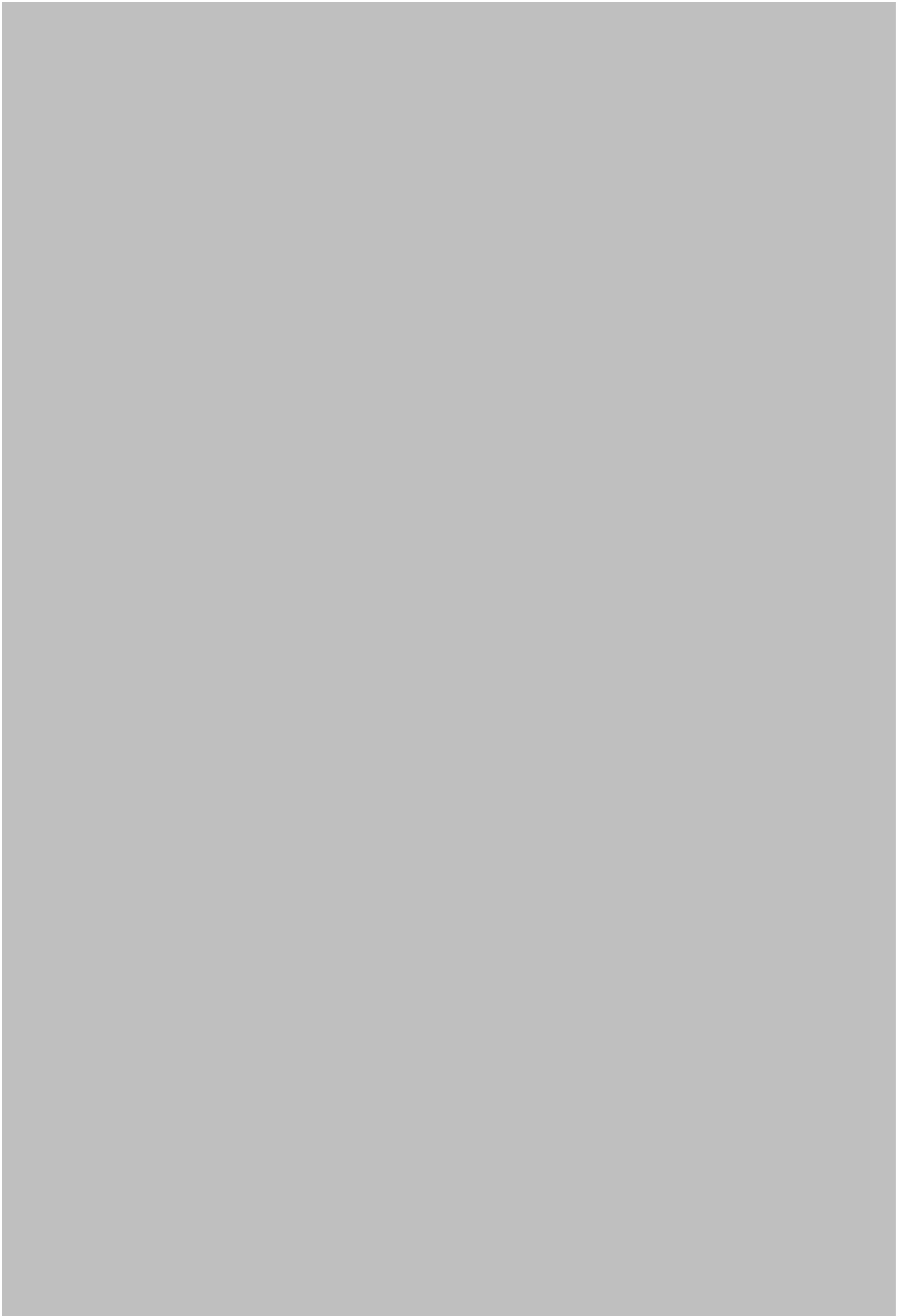
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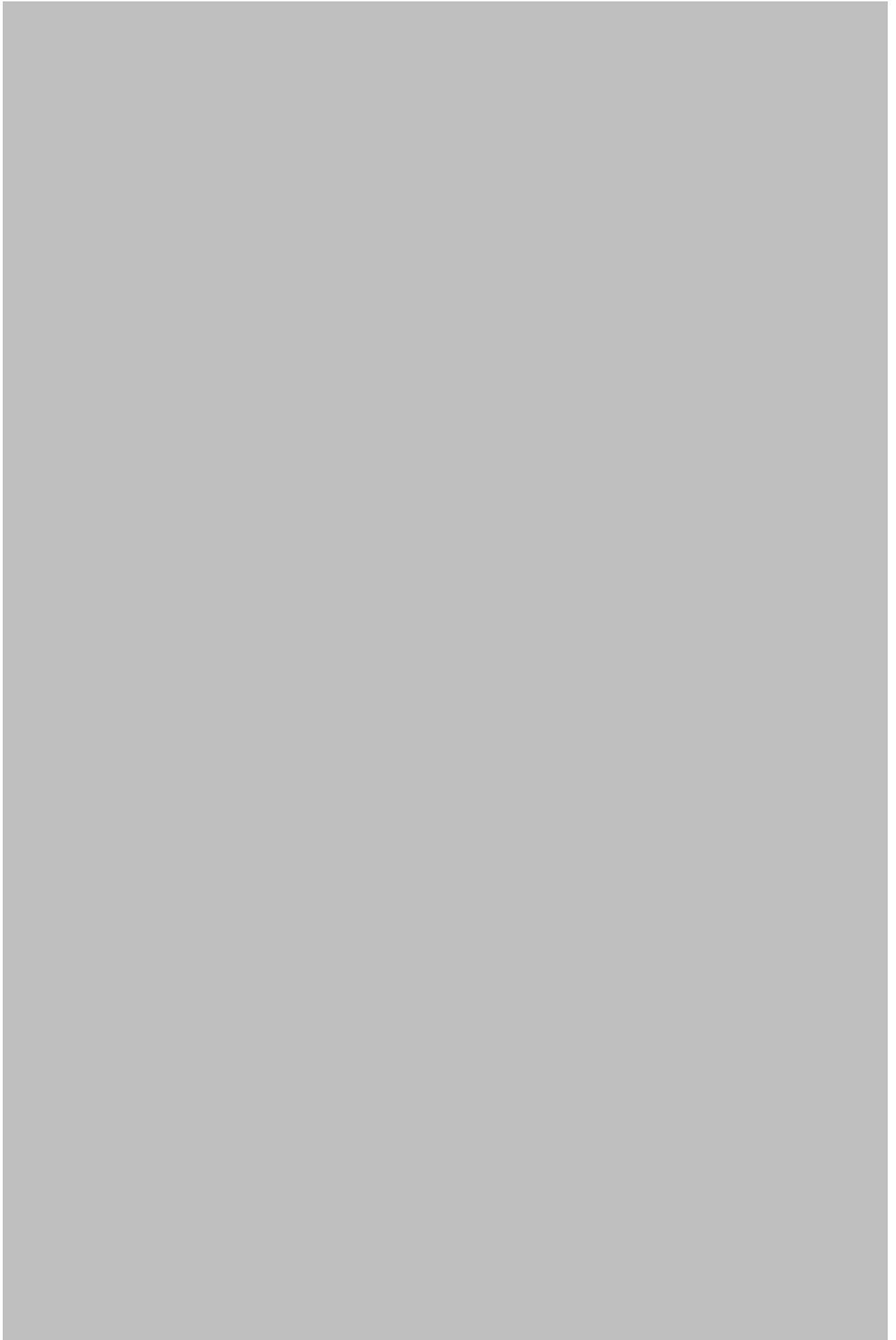
Appendix 1. Instructions to Authors from Psycho-Oncology

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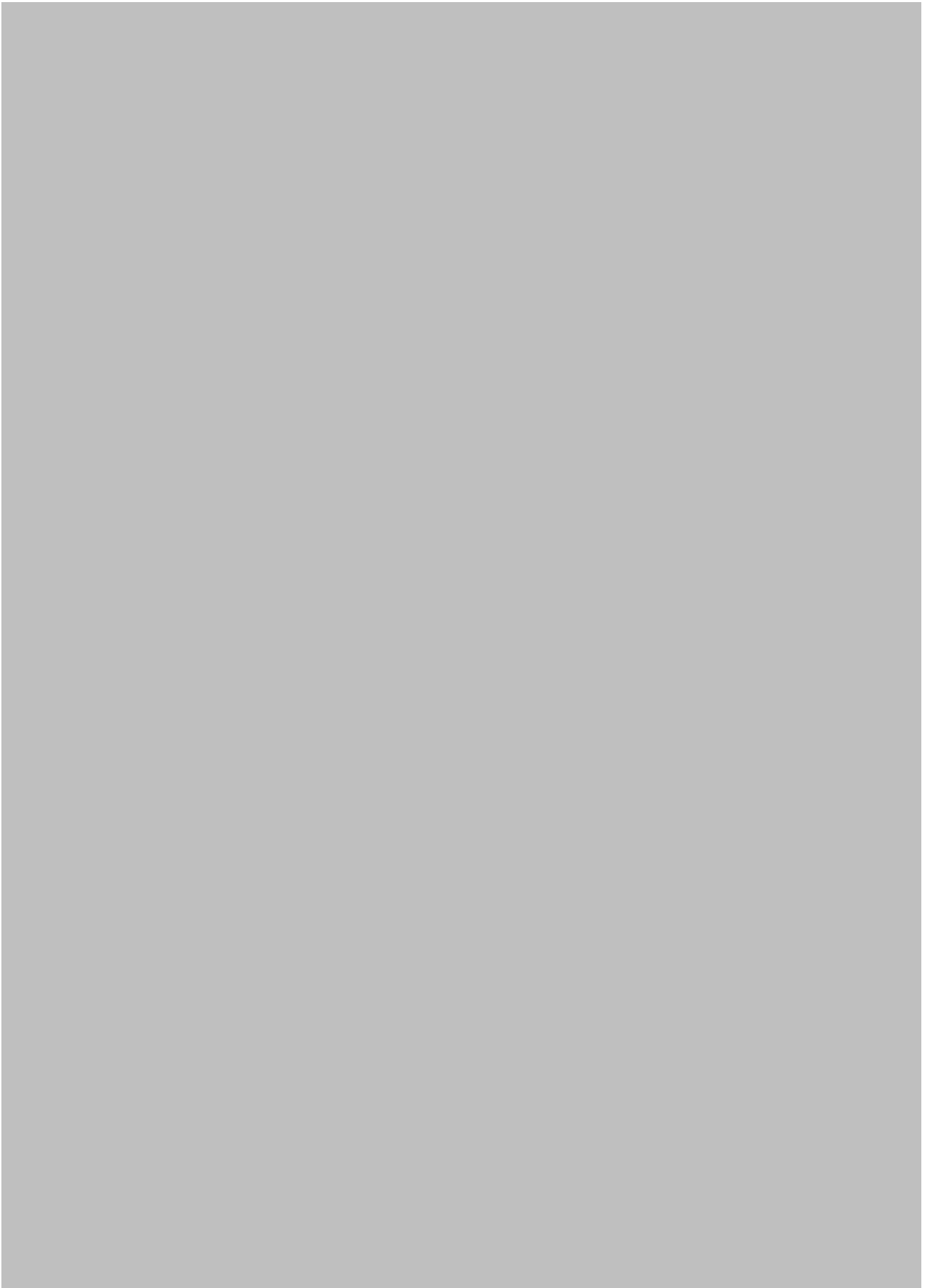


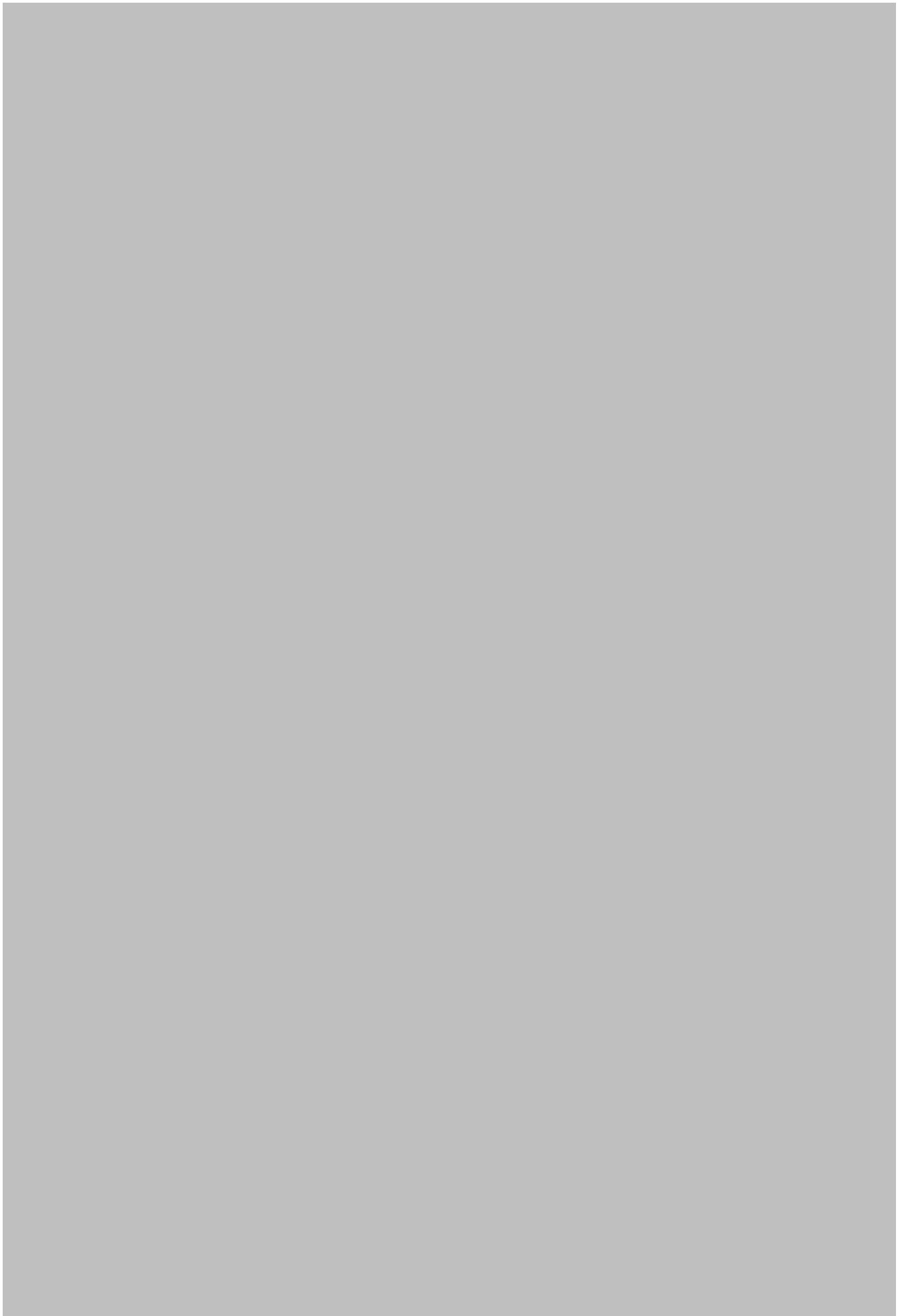


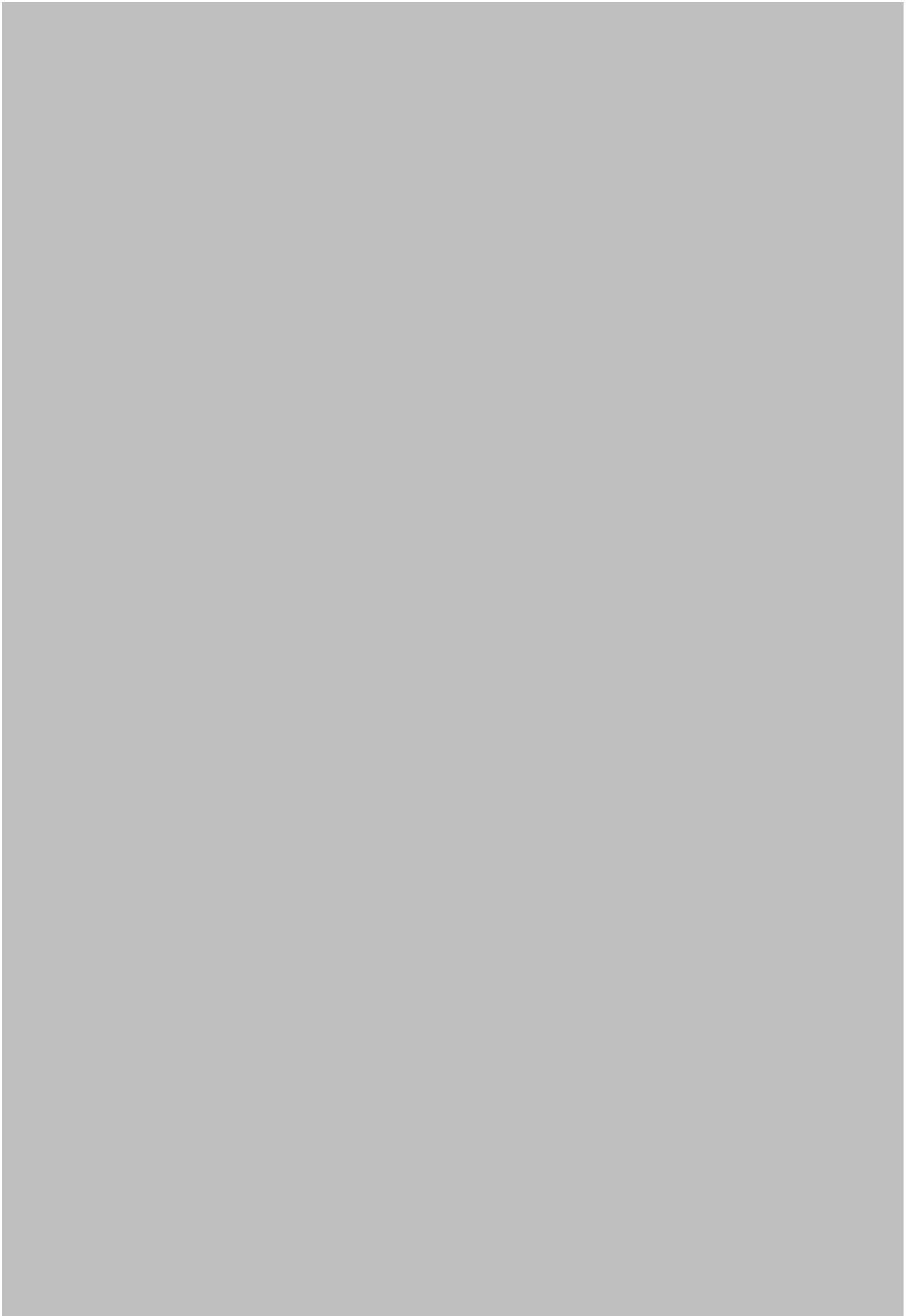
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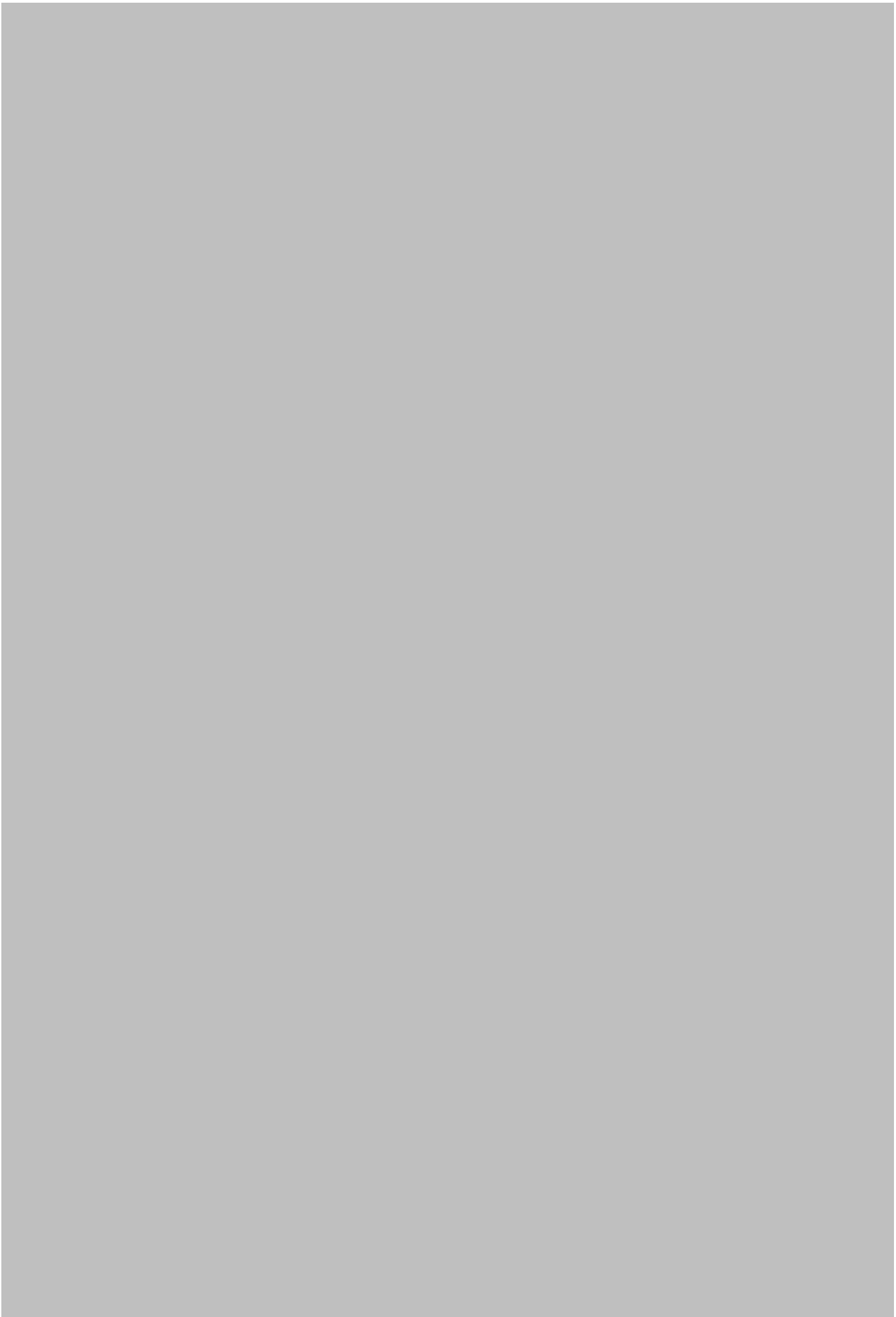
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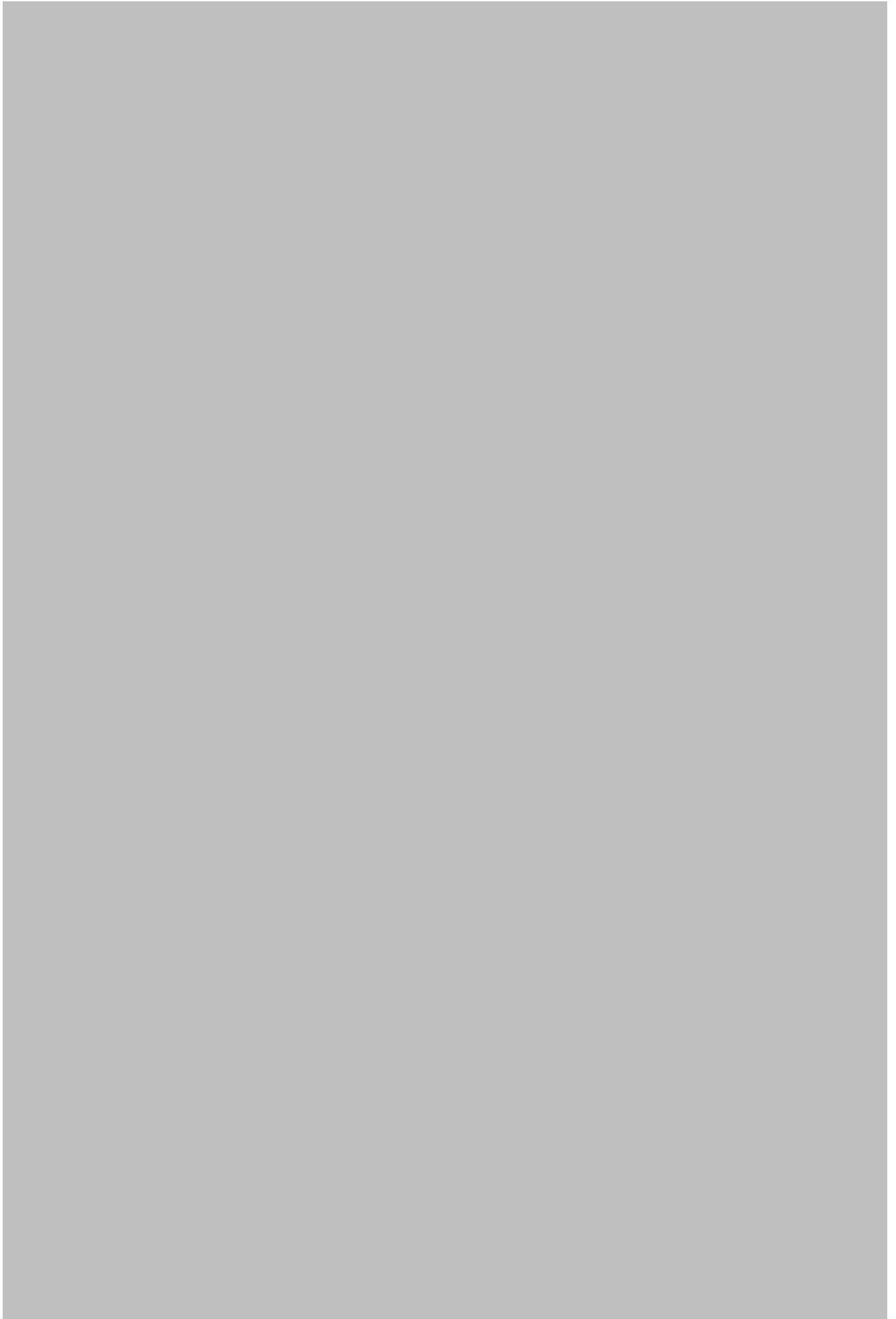


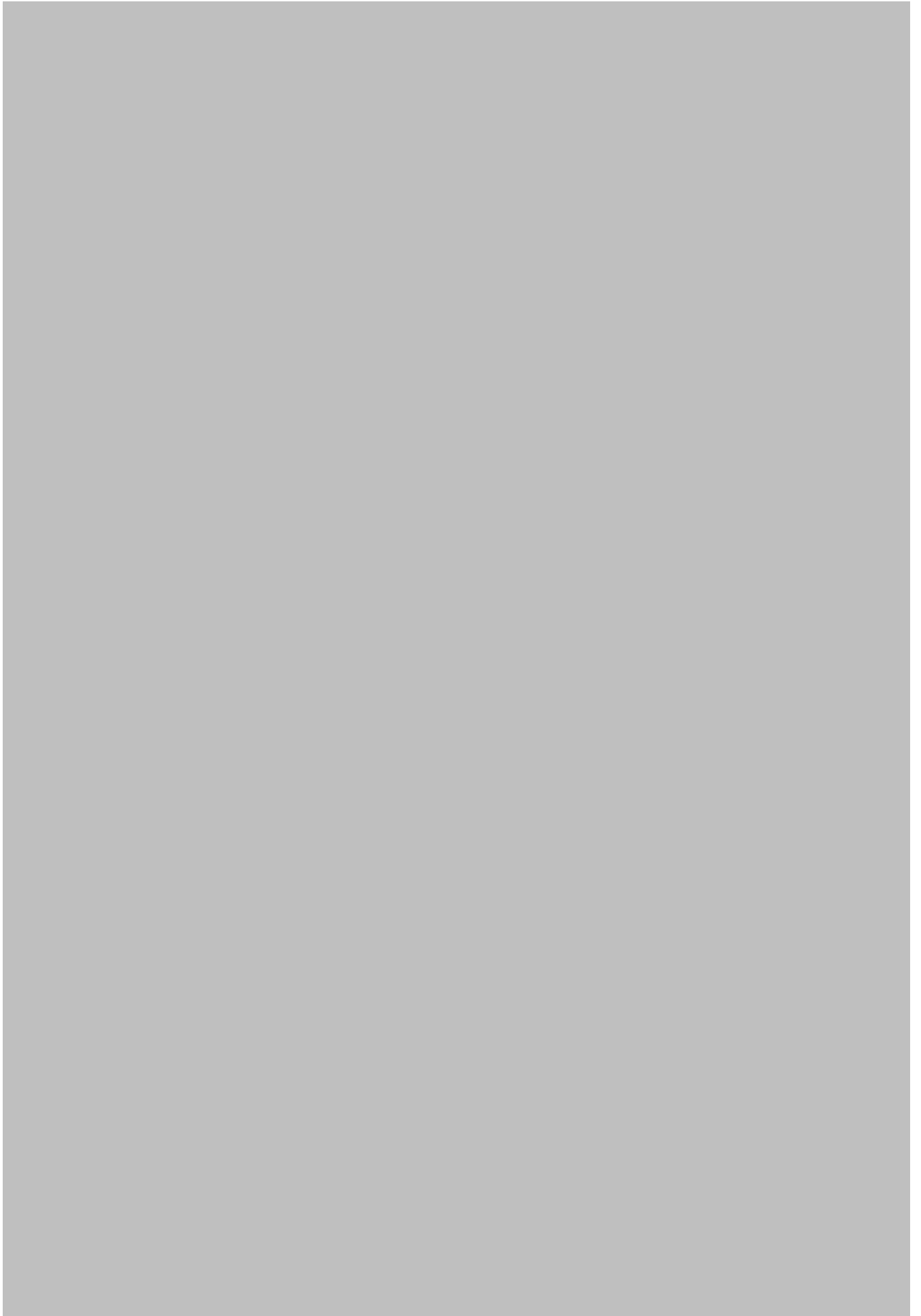


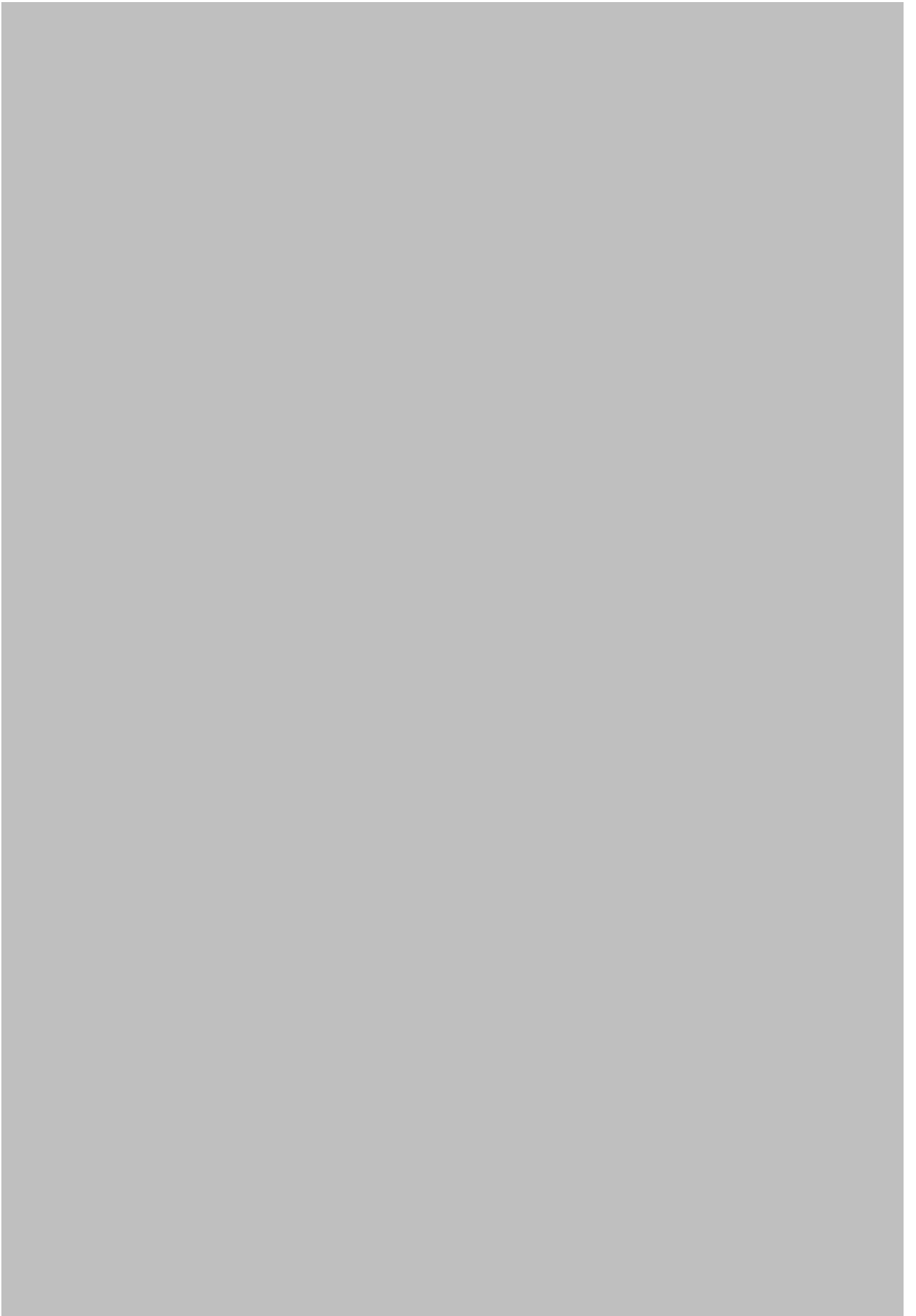


















Appendix 3. Documents relating to Ethical Review of this study





Appendix 4. Copy of Patient Information Sheet.

Fertility decision making in the context of breast cancer: a qualitative study of heterosexual couples' experiences and support needs

NRES Committee West Midlands -Coventry and Warwickshire ref 13/WM/0034

Participant information sheet

My name is Dr Eike Adams, I am a Clinical Psychologist in Training and also have a background in psychosocial cancer research.

You are being invited to take part in a research study. This information sheet will help you to understand why the research is being done and what it would involve for you.

Part 1 tells you the purpose of the study and tells you what will happen if you take part. Part 2 gives you more detailed information about the conduct of the study. Do talk about taking part in this research with your friends and relatives if you wish, and please take as much time as you like to decide if you would like to take part in the research. Also, please contact us if there is anything that is not clear or if you would like any more information.

Part 1

1. What is the purpose of this study?

The purpose of this study is to look at how couples make breast cancer treatment decisions, and what role fertility considerations play in this. It focuses on couples where the patient is under the age of 50. This study is part of my Clinical Psychology Doctoral degree.

2. Why have I been invited to take part?

You have been invited to take part in the study because your breast care nurse identified you as someone who has very recently been diagnosed with breast cancer, and who is aged under 50 and in a relationship.

3. Do I have to take part?

No. It is up to you to decide whether you would like to take part. If you decide to take part, you will be given this information sheet to keep, and a consent form to sign. You are free to withdraw at any time, without giving a reason. If you decide not to take part, or if you take part but later decide that you would prefer to withdraw, you will still receive the same standard of care.

4. What will I have to do if I take part?

Taking part would mean for yourself and your partner/ spouse to be interviewed by a trained researcher, in separate interviews. The interviews would be informal, completely confidential, and would last approximately one hour each. The interviews could take place in your own home or some other convenient place (whichever you prefer). If you agreed, the interview would be recorded.

The interviewer will ask you some questions about your diagnosis, your treatment

decisions, your fertility concerns, and your relationship and also any psychosocial support you have received and would like to receive.

If there were any questions you did not feel you wanted to answer, or if at any point you felt that you did not want to complete the interview then you would just need to let the interviewer know and your wishes would be respected

5. What are the possible benefits or disadvantages of taking part?

There may be no direct benefit to you from taking part. However, you will be informing service development in this area and this could help to improve services in the future for people with cancer and their families.

A possible disadvantage is that you may find it upsetting to think or talk about your own illness. If this happens you would be able to withdraw if that is your wish. You may also choose to contact your GP, or an organisation such as Macmillan Cancer Support or a Maggie's Centre who can provide information and support to everyone affected by cancer (please see 14. for contact details).

6. Expenses and payments

Any travelling expenses will be paid. A token of appreciation of a £10 High Street voucher will also be given for each completed interview.

7. What if something goes wrong?

Given the nature of this study, it is highly unlikely that anything will go wrong. However, any complaints you may have will be addressed. For further information see Part 2.

If the information in Part 1 has interested you and you are considering taking part, please read the additional information in Part 2 before making any decision.

Part 2

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

If you decide you no longer wish to take part in the study during the interview, you simply let the researcher know and the interview will end. You will also get the opportunity to check anything you have said in the interview after its completion, and to remove anything you do not wish to be used in the research. You will be able to do this up to 2 weeks after the end of your interviews. If you decide you wish to withdraw after the interview is finished, you simply have to complete the *Withdraw from Study* form at the end of this information sheet and return it to the researchers at the address provided. You can do this at any time until end of April 2014. Any information collected from you would then be destroyed. After that time, anonymous citations from your interview may have been used in published research and in my thesis.

9. What if there are any problems?

If you have any concerns about this study or the way it has been carried out, you can contact the researcher, Dr Eike Adams on [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]




10. Will my taking part in this study be kept confidential?

All of the information about your participation in the study will be treated in strict confidence, and will not be passed to anyone else. The research team has a duty of confidentiality to you as a research participant. Your name and contact details will be kept securely in a locked filing cabinet / in a password protected computer file.

Everything you say during the interview will be anonymous and treated in strict confidence. It will only be seen by the researcher on the study and her supervisory team. The recordings and transcripts (written records) of the interview will be kept in a locked filing cabinet and will have no name attached to them. Our procedures for the handling, processing, storage and destruction of all study data will comply with the Data Protection Act 1998.

However, you need to bear in mind that only a small number of couples will take part in the study. If you choose to read the final report, or a published paper from this study, all snippets from the interviews used with you will be anonymised. But you may recognise what you have said, and therefore might be able to work out what your partner or spouse may have said. After the interview, before any analysis, you have the opportunity to check your record of the interview to delete anything you may have said which you no longer want to be part of the interview.

11. What will happen to the results of the research study?

The results of this study will be used to improve the care provided by psychological cancer services to people diagnosed with cancer and their partners/ spouses. The study will help us to understand what sort of psychological support and information patients and their partners/ spouses would like from psychological cancer services, and how best to provide this.

We would intend to publish the findings of the study in a psychological journal. The overall interview findings would be included in the publication but this would be completely anonymous (i.e. your name would not appear anywhere in print). We will also ask if you would like to be sent a summary of the study findings and this will be sent when we have finished the study.

12. Who is organizing and funding the research?

The research is being conducted by the University of Birmingham.

13. Who has reviewed the study?

Birmingham University and a National Research Ethics Committee have reviewed the study and given it a favourable ethical opinion for conduct in the NHS.

14. Further information and contact details

If you would like any further information, or have any further questions concerning the research study you are encouraged to contact the study lead, Dr Eike Adams, on [REDACTED]. Should this study have raised any particular issues for you in relation to cancer you may wish to contact your GP practice or Macmillan Cancer Support (www.macmillan.org.uk or Freephone Helpline number: 0808 808 00 00). Macmillan Cancer Support is an organization which provides information and support for people with cancer and their family members

Thank you very much for taking the time to read this information sheet.

Withdrawal from Research form



Appendix 5. Copy of Patient Consent Form.

