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Qualitative Health Research

Unveiling the maelstrom of the early breast cancer trajectory

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ABSTRACT

Length and complexity of illness and treatment in early breast cancer mean that the acute phase may extend over months. Employing concepts of 'trajectory' and 'work' from chronic illness, we explored the temporality of the illness experience for women as it unfolded from diagnosis through acute treatment. We performed multiple, qualitative interviews with 14 women at critical points in their first year post-diagnosis. We differentiated between sub-phases of the acute breast cancer trajectory: becoming a person with breast cancer: a turning point; first steps in treatment: struggling to protect self-concept; being and feeling ill: 'cure' as suffering; and conditional 'recovering': an uncertain future. Each sub-phase represented the distinctive context in which illness management took place with consequences for the work women and those close to them engaged in, to manage the practical, emotional, relational and existential demands of an illness that intruded every aspect of their lives.

INTRODUCTION

Breast cancer is the most common cancer diagnosed in women worldwide (Jemal et al., 2011). In England, it accounts for around one third of new cases of cancer in women and women have a one in eight chance of a breast cancer diagnosis in their lifetime (Office for National Statistics (ONS), 2012). It affects women across the age spectrum. Nearly half of those diagnosed with breast cancer are aged 50 to 69; and it is the most commonly diagnosed cancer in young women (under 39 years). Between 1971 and 2011, the breast cancer mortality rate in England reduced by over a third despite a doubling of new cases per annum; and recent data indicate that one and five year survival rates have increased to 96% and 86% respectively (ONS, 2016).

These changes are largely attributed to early diagnosis and improved treatments. For example, in the UK, the NHS Cancer Plan (Department of Health, 2000) introduced a two-week referral pathway from presentation of suspect symptoms to specialist diagnosis, and a maximum 31 day wait from diagnosis to first treatment for all cancers. Sequential treatments from chemotherapy through radiotherapy, biological therapies and preventive medication extend treatment for many women over months and several years, resulting in side effects of varying type and duration. Thus the illness course and projected lifespan is longer and more variable, and the simple distinction between acute and chronic illness fails to capture the trajectory complexity (Tritter & Calnan, 2002).

The changes to routine disease management and development of novel treatment modalities which extend the illness course pose new challenges for women. These embrace the shifting meaning attached to breast cancer over time and the work involved in sustaining 'self' and managing the illness in everyday life. This article provides insight into the emergent character of early breast cancer as this unfolds in time for women through acute treatment;

1
2
3 and the inter-related strands of ‘work’ they engage in to simultaneously manage selves, lives
4
5 and relationships.
6

7 8 **BACKGROUND**

9
10 Qualitative research on the meanings of breast cancer for women and the existential, physical
11
12 and psycho-social effects of diagnosis and treatment has expanded over three decades.

13
14 Dimensions examined include: the effects of changed appearance (loss of breast and hair) on
15
16 body image and sexuality (Crouch & McKenzie, 2000; Harcourt & Frith, 2008; Richer &
17
18 Ezer, 2002; Thomas-McClean, 2010); the physical and emotional sequelae of treatment
19
20 (Oxlad et al., 2008), specifically radiotherapy (Schnur et al., 2009) and chemotherapy
21
22 (Beisecker et al., 1997; Boehmke & Dickerson, 2006; McCann et al., 2010), which persist
23
24 for some women long after treatment ends (McKenzie & Crouch, 2004; Thomas-MacLean,
25
26 2004; Trusson, Pilnick & Roy, 2016); and the socio-cultural context shaping the experience
27
28 (Hammoudeh et al., 2016; Liamputtong & Suwankhong, 2015). Research has also addressed
29
30 existential questions of life and death which give rise to fear and anticipatory suffering,
31
32 vulnerability and threat to self (Arman & Rehnsfeldt, 2003), although the pervasiveness of
33
34 suffering is contested. Landmark & Wahl (2002) conclude that although diagnosis provokes
35
36 anguish, anger and fear, these reactions are transitory; and others report the cancer experience
37
38 as ‘transformative’ (Browall et al., 2006) or opportunity for positive change (Horgan et al.,
39
40 2011; see also Price Herndl’s (2006) review of breast cancer autobiographical narratives).
41
42
43
44
45

46
47 A feature of many studies is that the temporal dimension of the breast cancer experience is
48
49 largely ignored. This applies at methodological and conceptual levels. Research on the
50
51 impact of diagnosis and treatment on sense of self may examine this cross-sectionally with
52
53 women at different illness stages (between two and 20 years in the Crouch & McKenzie
54
55 studies), so that the temporal structure of the experience and change process is rendered
56
57
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1
2
3 invisible. Studies exploring the persistence of suffering have often recruited through cancer
4 support groups (Thomas-MacLean, 2004; Powers, Gullifer & Shaw, 2016) or via national and
5 local media (Trusson et al., 2016), raising the possibility that participating women are those
6 for whom the experience is an ongoing source of distress. Within this expanding literature on
7 survivorship in breast cancer, accounts of diagnosis and treatment are conveyed often years
8 after the event (Thomas-MacLean, 2004; McKenzie & Crouch, 2004; Thomas-MacLean,
9 2004; Powers et al., 2016; Trusson et al., 2016). Even when examined at multiple time-
10 points following diagnosis, the change process may be captured only in large brushstrokes
11 (from health to illness as in McCann et al., 2010) or in respect of one dimension (bodily
12 changes in Frith & Harcourt, 2007; effects of adjuvant treatment in Boehmke & Dickenson,
13 2006). Understanding breast cancer within a temporal framework is critical not only to
14 comprehend the meaning of illness and impact of treatments that affect its course; but to
15 locate the work of managing it in dynamic relationship with the shifting character of the
16 disease and treatment regimen, and which in turn has implications for providing appropriate
17 and timely support.

36 **Conceptual Framework**

37
38 In framing the study we drew on linked concepts of ‘trajectory’ and ‘illness work’ as
39 developed by Strauss and colleagues from research on chronic illness (Corbin & Strauss,
40 1985, 1988). ‘Trajectory’ refers to the temporal quality of the illness experience as this is
41 shaped inter-alia by the physiological unfolding of the disease process and medical regimen,
42 and the inter-related strands of work engaged in by those who are ill and their significant
43 others to live with, adapt to, and manage it.

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Managing chronic illness, Corbin & Strauss (1988) argued, involves three main lines of
interconnected and reciprocally interactive types of ‘work’: biographical, illness-related, and

1
2
3 everyday life work. Biographical work is what people do to contextualize the illness into
4
5 their biography, making it part of an ongoing life. It is affected by the meaning of illness, the
6
7 context in which it occurs, and the resources available to the individual. Illness-related work
8
9 pertains to the illness and treatment regimen, including symptoms and treatment side effects.
10
11 A further line of work is managing everyday life and relationships with illness.
12
13

14
15 The nature and intensity of trajectory work will vary with illness severity, the type of
16
17 trajectory and its phasing within types, for example, whether the trajectory projection is
18
19 remitting, life threatening or deteriorating. The work of illness management then occurs in
20
21 conditions which are fluctuating and changing, what they term 'structure in process' to
22
23 indicate its structural and dynamic character. It is the interplay between efforts to gain some
24
25 control over these conditions and respond to contingencies, whether anticipated or
26
27 unexpected that affect the illness course, which shape the phases and sub-phases of different
28
29 trajectories.
30
31

32
33 The significance of the trajectory concept is that it directs attention on individual agency in
34
35 illness adaptation albeit in conditions established by the disease process and treatment
36
37 regimen. Understanding the precise phase or stage that a condition undergoes over its course
38
39 is crucial to gaining an accurate picture of the associated types of work and resources to
40
41 facilitate its management, and which in turn shape its meaning and consequences. Regarding
42
43 early breast cancer, the trajectory concept provides a sensitizing framework to examine the
44
45 temporal dimension of the experience for women, the conditions that shape it and the
46
47 consequences that flow from it, uniquely in context of the acute illness phase. It also has
48
49 potential to illuminate need and supportive resources at key turning points within and through
50
51 trajectory sub-phases.
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RESEARCH DESIGN

This article draws on multiple, qualitative interviews with women with early breast cancer. Data were collected as part of a longitudinal, intervention study to examine the theory and practice of traditional acupuncture (TA), using early breast cancer as an exemplar of a complex condition. The interview purpose was to locate the process and outcomes of acupuncture in context of women's experience over the acute breast cancer trajectory phase and to provide insight into the meaning, significance and consequence of illness and treatment as it unfolded in time. Thus, focus extended considerably beyond perceptions of acupuncture in content and timeframe. Women were recruited from two hospitals in neighboring Northern English cities: a specialist regional cancer center and a district teaching hospital; and introduced to the study via their oncologist. Ethical approval was obtained from the research ethics committee which provides ethical review of health-related research in the United Kingdom (Reference: 07/HI306/79). Written consent was obtained. Methods, details of participants and findings of acupuncture care have been reported elsewhere (Price, Long & Godfrey 2013; 2014).

Data Collection

35 in-depth interviews with 14 women, lasting between 50 and 120 minutes, audio-recorded and fully transcribed were conducted across three time points: after first line surgical treatment and 7-10 days before chemotherapy commenced; approximately four months later toward the end of chemotherapy; and around five months subsequently following adjuvant treatment. For resource reasons, third interviews were conducted with seven women only, purposively selected to examine variation in meaning and experience for women at different life stages and undergoing different treatment regimens. With one exception, interviews took place at two cancer support centers; one occurred in hospital. Interviews were guided

1
2
3 conversations. The first started: *'Tell me how you discovered you had breast cancer?'* It then
4
5 explored the impact of diagnosis and surgery; how it was understood and felt for women and
6
7 those close to them in context of their lives and relationships; and anticipation of future
8
9 treatment. The second began *'How have things been for you in the last few months?'* It
10
11 elicited accounts of chemotherapy and its consequences for their sense of self and what they
12
13 could do including accessing and receiving support from family and friends. The third
14
15 started: *'How are things for you now?'* and then probed subsequent treatments; what had
16
17 changed and what remained the same. Timing of interviews facilitated near-experience
18
19 accounts of what went before in vivid detail, how these shaped meaning and (inter)action in
20
21 the present; and which in turn were informed by anticipated fears and hopes for the future.
22
23
24
25 Women were aged 29 to 75 years, mostly White British and varied in their socio-economic
26
27 circumstances. Although all were enmeshed in family relationships, household composition
28
29 and family circumstances varied with age and life stage (Table 1).
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Table 1: Total Participant Characteristics

Age	
Under 30	1
30-40	-
41-50	4
51-60	4
61-70	4
71-80	1
Marital Status	
Married/Partnership	9
Widowed	2
Separated/Divorced	2
Household Composition	
Alone	5
With partner/spouse	4
Partner and young children	2
Partner and adult children	2
With parents	1
Occupation at Diagnosis	
Managerial	1
Small business owner	1
Professional	3
Clerical	4
Not in employment	2
Retired	3

Data Analysis

We employed grounded theory methods in collecting and analyzing data (Charmaz, 2014).

Field notes, including observational, methodological and reflexive notes, were made immediately after each interview. These together with fully transcribed interviews were discussed within the research team and suggested new lines of enquiry. For example, initial interviews revealed a kaleidoscope of conflicting meanings of the breast cancer experience encapsulated in the phrase: *everything and nothing had changed with the diagnosis*. This directed attention on women's presentation of self to different 'others', exploration of

1
2
3 seemingly contradictory meanings and actions, how these changed over time and in relation
4
5 to the unfolding illness context, for women in difference circumstances.
6

7
8 Further phases included familiarization of the dataset through multiple reading of transcripts
9
10 to develop a picture of range and variability; and open coding to identify patterns with focus
11
12 on the temporal sequencing of events and how these were understood. We analyzed a sample
13
14 of audio interviews and transcripts independently to review the inferences and interpretations
15
16 drawn from the data. At each analytic stage – development of codes, categories, concepts
17
18 and the relationships between them – discussion within the research team occurred to further
19
20 refine these through iterative reflection and perusal of the data. Privacy, anonymity and
21
22 confidentiality were upheld at all times, and pseudonyms have been used throughout.
23
24

25
26 While the ‘trajectory’ concept offered orienting guidance in examining the empirical data
27
28 (Blumer, 1969; van den Hoonaard, 1997), we employed methods of constant comparison and
29
30 search for negative cases to examine its specific meaning in early breast cancer. We
31
32 identified potentially fruitful analytic codes to pursue through focused coding and memos.
33
34 For example the ‘in-vivo’ code ‘being normal’ was developed as an analytical category.
35
36 Comparing and contrasting accounts and incidents between individuals and over time, we
37
38 explored its properties, the conditions that shaped it, the emotional and interactional strategies
39
40 that sustained it and the disease process and treatment regimen that challenged it.
41
42
43

44 **FINDINGS**

45 **THE EBC TRAJECTORY**

46
47
48 The acute EBC trajectory comprised several sub-phases: *becoming a person with breast*
49
50 *cancer: a turning point; first steps in treatment: struggling to protect self-concept; being and*
51
52 *feeling ill: ‘cure’ as suffering; and conditional ‘recovering’: an uncertain future.* These sub-
53
54 phases were shaped inter-alia by the life threatening character of the diagnosis, the
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1
2
3 anticipated and actual illness course and treatment regimen, and the struggle to make sense of
4
5 it all. Length and treatment regimen varied. Three women had a mastectomy reflecting its
6
7 current more differentiated use in treating breast cancer; the rest had a lumpectomy. While
8
9 everyone received chemotherapy, acute treatment was prolonged by radiotherapy for more
10
11 than half of women, including three who were prescribed biological therapy (Herceptin). For
12
13 most women, the phase from diagnosis to the conclusion of acute treatment lasted up to 12
14
15 months, extending over a further year for those on Herceptin infusions. Each sub-phase was
16
17 distinctive in its meaning for participants; in its consequences for sense of self and for
18
19 managing illness and daily life; in the feelings generated; and the emotion work involved in
20
21 coming to terms with it for women and those close to them.
22
23
24

25 26 **Becoming a Person with Breast Cancer: A Turning Point**

27
28 Unlike most illnesses, 'becoming a person with breast cancer' unfolded over the diagnostic
29
30 process. The starting point of the trajectory, as recounted by women in the first interview,
31
32 was the discovery of a lump in the breast. For most women, this occurred accidentally when
33
34 showering or bathing; for two women the process commenced following a routine
35
36 mammogram. In all cases, the 'discovery' precipitated multiple and sequential medical
37
38 encounters. In absence of signs of illness, women listened and looked for verbal and non-
39
40 verbal cues from medical professionals as to what might be going on, eschewing direct
41
42 questions, anticipating and fearing the certainty of a cancer diagnosis. The speed of referral
43
44 from general practitioner to hospital was the first intimation that it might be serious. Then
45
46 successive investigations - mammogram, ultra-sound and biopsy – ratcheted up women's
47
48 anxiety, being 'read' as cumulative evidence of their worst fears being realized.
49
50
51

52
53 The GP didn't say a lot actually; she felt it and said: "yes there is something"...I just
54
55 thought she might say: oh a lot of these things are benign. But she didn't say
56
57
58

1
2
3 anything...just that it needed to get checked...which ... bothered me ... A week later I
4
5 got an appointment... So it's all a waiting game right from the beginning...Everything
6
7 seems to take so long (sighs) although it's not in reality.
8
9

10 Although in elapsed time, the diagnostic process was completed within a short timeframe
11
12 (several weeks), it felt protracted and lengthy.
13
14

15 In this interview, women wept as they talked of their pain on being told they had breast
16
17 cancer. Similar to others (Evans et al., 2006; Walsh & Nelson, 2003), communication of
18
19 the formal diagnosis was perceived as a pivotal and defining moment in their biography.
20
21 Time, place and context of diagnosis were conveyed in vivid detail, reinforcing the
22
23 meaning of the cancer diagnosis as constituting a turning point or 'critical situation', in
24
25 which "*the structures of everyday life and the forms of knowledge which underpin them*
26
27 *are disrupted*" (Bury, 1982:169).
28
29

30
31 I got a phone call from my GP ... filling my trolley in the supermarket...and my world
32
33 just came to a crashing halt. It was like a train, a fast moving train just stopped on
34
35 January 2nd... that was the start of ... my life, the second part.
36
37

38 The short time between diagnosis and surgery – approximately two weeks – was a period of
39
40 intense emotionality as women's fears bubbled up in uncontrollable tears. While they
41
42 perceived the diagnosis as irrevocably altering their sense of themselves, its consequences for
43
44 how they experienced their bodies and for what they could do, was in the future. In this
45
46 respect, the body had not yet become a site of illness. Rather, the incongruity between the
47
48 trajectory projection of a potentially life threatening illness and the fact that they did not feel
49
50 ill contributed to the maelstrom of emotions – shock, devastation and disbelief –
51
52 experienced.
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55
56
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58

1
2
3 I wasn't ill, that's the thing; when I went to hospital to have surgery...I was in perfect
4
5 health.
6

7
8 The knowledge that cancer was growing inside unbeknownst to them provoked confusion and
9
10 anger: at the failure of the body to signify impending threat and that they had taken it for
11
12 granted.
13

14 15 **Relational impact of cancer**

16
17 Women's diagnostic journey occurred relationally in that everyone was accompanied to
18
19 investigations and subsequent medical appointments by someone close, typically a partner,
20
21 adult daughter, sister or parent. Embedded in intimate and personal relationships with
22
23 partners, children, siblings, parents and friends, women acknowledged that the illness would
24
25 affect these significant others in its portent of loss and meaning for a shared future.
26
27

28
29 Nevertheless, the process whereby women sought practical and emotional support, and to
30
31 whom they communicated emotions and needs was affected by not wanting to impose an
32
33 undue burden; and was negotiated within broad normative constraints. Whereas practical
34
35 assistance was drawn from a wide circle, the nature of the relationship set the parameters
36
37 around who women perceived as appropriate to share fears and distress. Partners/spouses
38
39 were viewed as primary confidantes and sources of emotional support. Women were more
40
41 circumspect about disclosing vulnerability to adult children seen as reversing the natural
42
43 order of the relationship. One woman said: "*my partner gets more of my being scared*"
44
45 whereas her adult daughter, with whom she was very close, did not, "*because I am her Mum*
46
47 *...I'm the strong one*". Contextual factors challenged such relational assumptions. Women
48
49 were ambivalent about seeking emotional support from adult children, not wanting to "*give*
50
51 *the pain to them*". Where the relationship was close and women felt a need for someone to
52
53 'hear' and 'interpret' what medical professionals were saying, they involved them in medical
54
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1
2
3 encounters. In contrast, a young women still living at home regarded her mother as her
4
5 primary confidante and a source of strength.
6

7
8 Even as they drew on emotional support from significant others, protecting them from aspects
9
10 of illness burden shaped how and to what extent details of the illness were conveyed. One
11
12 woman's husband went with her to all out-patient appointments. Following the lumpectomy,
13
14 she purposively went alone for the results, fearing bad news.
15

16
17 I spared [him] that... I thought I'd rather go home, sit him down and tell him myself,
18
19 because he would have been devastated listening to the doctors saying that the breast
20
21 has got to come off. I don't think he'd be able to live with that really.
22
23

24
25 There were also those significant others deemed 'vulnerable' and with whom the diagnosis
26
27 was not shared, because of a desire to protect them, for example aged parents: what would be
28
29 the point; they would only worry.
30

31 **First Steps in Treatment: Struggling to Protect Self-Concept**

32
33
34 During this sub-phase spanning surgery and its immediate aftermath, women conveyed a
35
36 rollercoaster of emotions. Even as they described the cancer diagnosis as cataclysmic and
37
38 life changing and had just gone through appearance changing surgery, women, in this first
39
40 interview, presented their self-concept as unchanged. Surgery had excised the cancer. They
41
42 were their 'normal' selves, not defined as cancer 'victims' ('being normal'), working at
43
44 resuming their everyday routines ('doing normal'); and supported by close family and friends
45
46 in being cared about and not cared for ('relating normal'). Nevertheless, the disparity
47
48 between their presentation of selves and lives as 'normal' or at most of having undergone a
49
50 temporary change was belied by the rawness of their emotion, their inability to control its
51
52 expression and the weight of the emotional work to sustain hope of recovery.
53
54
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2
3 **'Doing normal'**: In the immediate aftermath of surgery, women reluctantly accepted help
4
5 from family with daily life routines as a consequence of pain, reduced movement and fatigue.
6
7 Where partners assumed most of the household tasks post-surgery, within weeks there was a
8
9 gradual shift back to their usual pattern. Women who prior to diagnosis were in
10
11 employment, anticipated that they would resume work in the foreseeable future. Conveying
12
13 need for help as temporary and that 'normal' life would resume in time was supportive of a
14
15 construction of self as unchanged. For several women, contingencies such as need for further
16
17 surgery or complications that extended the period of recovery, challenged but did not
18
19 fundamentally alter their presentation of self as 'normal'.
20
21

22
23 Even so, the cancer diagnosis invested new meaning for women in seeking out and accepting
24
25 practical and emotional support from significant others. This was presented simultaneously
26
27 as recognising the need for, and ambivalence about receiving help:
28
29

30
31 I'm used to doing an awful lot on my own... I have let people into this...including my
32
33 partner... more than I've done before....When you're not used to asking for help, it's
34
35 quite hard to do it.
36

37
38 Women were distressed about needing to be '*looked after*'. Their primary anticipatory
39
40 fear regarding chemotherapy was prolonged dependence on others. Foreshadowed nausea,
41
42 sickness, tiredness/fatigue and pain were viewed as a threat to resuming 'doing normal'.
43
44

45
46 I can cope with pain and surgery and fighting back and getting fit again but I can't bear
47
48 feeling ...so unwell during chemo that I can't get on with my life.
49

50
51 At the same time, they talked of getting on with chemotherapy, willing to try anything that
52
53 might help and downplayed its potential impact on appearance. In contrast to other studies
54
55 which report anticipation of hair loss as among the most common, feared consequences of
56
57 chemotherapy, particularly among younger women (Frith et al., 2007), the pattern here was
58

1
2
3 variable. Both older and younger women asserted that they were unconcerned about hair
4
5 loss.

6
7
8 Bald is beautiful.

9
10 And,

11
12
13 I'm not bothered about the loss of my hair, I have loads.

14
15
16 Those who anticipated hair loss as worrisome referred to its significance as a visible marker
17
18 of 'cancer victimhood' to the external world; they hoped to avoid it with 'cold cap' treatment.

19
20
21 **'Relating normal':** Women emphasized the value attached to family and friends relating to
22
23 them as if nothing had changed. Natasha noted that her family "*don't walk on egg shells*
24
25 *around me, which is good*"; and Julie's partner had "*found the right balance*" by being
26
27 supportive "*in a discreet way*". Some were explicit about how they wanted others to act
28
29 toward them as:

30
31
32 When I told relatives they was shocked and started to look sad and, you know, crying,
33
34 and I says: look I do not want anyone around me who is weeping... if you are coming
35
36 to see me, you cry before you come or you cry after you've seen me... I want just
37
38 positive people around me... so they stuck to that.

39
40
41 They acknowledged that relating to them as 'normal' did not mean that significant others
42
43 were unaffected emotionally. Several women spoke of being aware that partners and close
44
45 relatives "*did their share of crying*" alone (as they did), as they reassured those others that
46
47 they themselves *were "fine."* One participant described catching her younger brother sat in
48
49 the kitchen crying and she wanted to hug and reassure him. She felt her mother was "*copied*
50
51 *quite well ...with me... I suspect when she is on her own, she is being, you know (long pause)*
52
53 *different.*" 'Relating normal' then involved a level of mutual and reciprocal suppression of
54
55 distress, albeit in an open awareness context.

1
2
3 **'Being normal':** Women's presentation of 'doing' and 'relating' normal, were contributory
4
5 to, and reinforcing of their self-concept as unchanged. The work of reinforcing the 'normal'
6
7 self included talking about 'ordinary' things and avoiding situations in which others acted
8
9 toward them as if they were 'different'. Yet, this assertion of 'being normal' could not be
10
11 read off un-problematically from women's talk. It was intertwined with what they wanted to
12
13 be:
14

15
16 I don't want to be an ill person; I just want to be normal I suppose. So that's what I'm
17
18 trying to do.
19

20
21 It was also undermined by bursts of uncontrollable emotion that brought center stage the
22
23 impact of having cancer.
24

25
26 I feel as if I have accepted it, until I talk about it and then it's like I can't go back to see
27
28 the girls at work because I know I will be too upset... (Weeping)... It's like I've just
29
30 pushed it, and think I'm dealing with it and I'm ok, and then like now... because I'm
31
32 talking to you I'm feeling it again.
33
34

35 36 ***Working at 'normal': emotion work***

37
38 For women during this sub-phase, sustaining 'normal' with regard to self-concept and in their
39
40 relationships with significant others, involved considerable work. This was directed at
41
42 managing the maelstrom of emotions flowing from their fears of an uncertain future,
43
44 awareness of the distress of close others and their desire to protect them, as significant others
45
46 also sought to protect them.
47
48

49
50 Women conveyed in their talk that they had to keep positive *'to beat the cancer'*. It was what
51
52 was expected of them to actively manage their illness; it would also likely improve their
53
54 chance of recovery. But keeping positive did not guarantee recovery:
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2
3 I am just trying to remain positive...I feel like a coiled spring...when I do feel relaxed I
4 think I shouldn't because of wondering what is going to happen ...in my mind I know
5 that is sillybut nobody can predict what will happen...it's the uncertainty now.
6
7
8
9

10 It was also hard work:

11
12 I'm trying [to be positive] I've struggled with it but at least it is another of those things
13 that I feel like I am trying to do something for myself...but you would be a fool to say it
14 doesn't get to you...but then there is nothing definitive in what your life is going to be
15 ...so you get on with it and make the best out of it.
16
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22 Being positive was work in relation, in that women enjoined significant others in a
23 reciprocal, mutual endeavor directed at regulating intense emotions to promote positivity –
24 even if they did not unambiguously embrace it.
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28

29 I am still looking and thinking positively [pause], at the moment.
30
31

32 The downside of work to keep positive was that open expression of distress was muted and
33 deepest fears were hesitantly, if partially, shared with significant others, echoing research
34 conducted with caregivers (Lindholm et al., 2002). There were costs then to 'keeping
35 positive' and the benefits in reducing uncertainty were not secure.
36
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41 These conflicting and chaotic accounts during this sub-phase reflected women's emotional
42 turmoil and doubts about an anticipated future, even as they conveyed disruption to their
43 daily lives as temporary and their sense of self as unchanged. Within the same interview,
44 they questioned whether the cancer had been excised; embraced chemotherapy as a necessary
45 tool in the medical armory to take and keep the cancer away; anticipated side effects as
46 'grim'; and reckoned treatment was time limited.
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Being and Feeling Ill: 'Cure' as Suffering

The second interview occurred before the final chemotherapy cycle. The start of lengthy adjuvant treatments marked this sub-phase. With one exception, women experienced the physical reality of illness which affected every aspect of their lives, rupturing narratives of 'normal'.

Normality disrupted

For most women, manifestation of illness during adjuvant treatment exceeded their worst fears. The cumulative impact of multiple and varied effects of chemotherapy - nausea, fatigue, mouth ulcers, constipation, night sweats, feeling bloated and lack of sleep - punctured their attempts to present lives and selves as 'normal'. They found it difficult to convey a coherent picture of what 'being ill' was like because "*it changes so much of your body*".

That frightened me to death...and feeling so helpless.

The rhythm of the chemotherapy regimen meant that the intensity of 'being ill' ebbed and surged over each treatment cycle. Its lengthy duration, extending over six cycles, resulted in treatment and its effects dominating their lives; it was lost time. During the three weeks between treatments:

You change so much from being so ill to almost being well again and then to being ill the next day and it fluctuates so much that you can hardly remember how you felt. Then it starts again...and one of the worst things is taking yourself to have it done because you know it is going to make you so ill and watching it going in.

Many spoke of a disabling fatigue which was like nothing they had ever experienced. It was an all-encompassing tiredness that neither resulted from activity nor productive work and which sleep did not touch. The lassitude and whole body torpor was exacerbated by night

1
2
3 sweats which also contributed to disturbed sleep. However much women valued 'doing
4 normal', it wasn't sustainable: they relied on family to assume most routine daily life tasks.
5
6

7
8 Being dependent on significant others was felt as a diminution in self-image:
9

10 I feel like another person. I felt like I'd lost me. I'd disappeared somewhere. The 'me'
11 that is confident and independent and gets on with stuff had disappeared into this timid
12 little person who was completely dependent on [partner] to sort things out for me. And
13 ...that was difficult because that wasn't me. And I couldn't figure out where I had
14 gone.
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16
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20

21
22 They looked different - to themselves and others. They mourned their changed appearance
23 including those who made light of it at first interview.
24
25

26
27 Yeah the chemo has brought me down a lot, not just my strength. I don't like to see
28 myself in the mirror. I think I look horrible...I am weak and tired and ugly.
29
30
31

32 One of the two women who had a mastectomy, initially downplayed loss of her breast: it
33 served no useful function as she'd had her children. Now she felt part of her was gone, like
34 losing a limb, with additionally feeling unattractive to her husband: "*my self-esteem has hit*
35 *rock bottom*".
36
37
38
39

40
41 Their need for emotional support while protecting significant others from their pain,
42 exacerbated women's distress:
43
44

45
46 You don't want to appear ill in front of the family; you don't want the family to know
47 how bad it is. But you can't help it [weeps gently].
48
49
50

51 Despite their best efforts, 'doing', 'relating' and 'being' normal were impossible to sustain.

52
53 Even as they expressed hope that 'being ill' was a consequence of treatment, and that their
54
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1
2
3 changed appearance would reverse in time, resumption of 'normal' was tinged with
4
5 uncertainty.
6

7
8 In the back of my mind, I'm worried about the future.
9

10 For several women, experience of a pivotal contingency or sets of contingencies reduced or
11
12 extinguished all hope of resumption of 'normal'. One woman reacted badly to the first
13
14 chemotherapy cycle and then suffered a stroke resulting in interruption of treatment and total
15
16 reliance on her daughter. Whereas in the first interview she had described multiple health
17
18 problems from which "*she bounced back ...just got on with it*", she now despaired at her
19
20 dependence, mourned loss of an active life and feared a future marked by deterioration.
21
22
23

24 **Continuity of 'normal'**

25
26 Some women asserted that their journey through treatment was 'no big deal'. For one
27
28 woman, this reflected reality. Uniquely among participants although her hair thinned, she
29
30 didn't lose it, and apart from the odd day feeling 'off', she described sailing through
31
32 treatments:
33
34

35
36 I've never been ill; I've never looked ill... and I've carried on doing all the housework
37
38 and driving...and just a bit of time off work.
39
40

41 The congruity between 'being' and 'doing' normal sustained her sense of an unchanged
42
43 self. Nevertheless, fear of the cancer recurring was an ongoing presence; emotionality
44
45 persisted as did the work of protecting her family from her distress.
46
47

48
49 I cry but not normally in front of my nearest and dearest...my husband and
50
51 children...and my Mum...I do all my crying with other people.
52

53 Other women here, conveyed life as 'normal,' although their contradictory narratives of
54
55 'being ill' belied such accounting.
56
57
58

1
2
3 At the beginning of the second interview, one such woman commented that she had
4
5 experienced no strong chemotherapy side-effects. Later, she described fatigue in vivid terms,
6
7 distressing in its impact and with consequences for what she could do. Her body was being
8
9
10 “drained and literally just walking around the house, when it is at its worst, is an effort.” She
11
12 tried and failed to work through it. Stretching herself physically to sustain 'doing' normal in
13
14 the home, she rarely went out alone, fearing being overcome by fatigue.

15
16
17 Another similarly played down ‘feeling ill’ while describing night sweats and disrupted sleep
18
19 that were at the most debilitating end of the spectrum.

20
21
22 Night time ones ...where it just drips off you, my body, my head...it just pours off my
23
24 head...and I would be wringing wet through... It would last for about 20 minutes. I
25
26 would go into the bathroom and get the cold flannel...and as soon as I’d cleaned myself
27
28 off and lay down it would come again and I’d get up between five and eight times in
29
30 the night.
31

32
33 Several factors in dynamic relationship contributed to ‘normalizing’ illness for these women
34
35 during treatment. They struggled to remain strong, construed as “*not being emotional*” so as
36
37 to keep positive and not succumb to negativity. This in turn required that they convey to
38
39 close others that everything was well. However, identity claims around ‘being’ and ‘doing’
40
41 normal and downplaying the physical and emotional impact of illness, had the effect of
42
43 reducing access to relational support.
44
45

46
47 I will say everything is fine...but sometimes it’s not...like I hold things in...and then
48
49 get depressed. I didn’t want my partner and daughter fussing over me...and told them
50
51 so... now they treat me as if there is nothing wrong with me... I feel how long am I
52
53 going to live; has it travelled to another part of my body...that’s what I think but my
54
55 family don’t know that...they think that I’m cured...I mean I suppose I am aren’t I?
56
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1
2
3 For some of these women, the effort of holding on to 'normal' despite the effects of illness
4 was only sustained by maintaining a level of social and emotional distance from significant
5 others. This extended to closing themselves off from professional support and from other
6 patients during treatment sessions at hospital out-patients: face in a book and ears plugged to
7 music, they blocked out sight and sound of patients and staff.
8

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10
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14 Others here employed the strategy of social comparison to normalize symptoms, seeing
15 themselves as not suffering as badly as other women they knew. One woman, for example,
16 who similarly underplayed the effects of chemotherapy, also described multiple physical
17 symptoms in every part of her body: mouth, stomach, bones, appearance. Comparing her
18 experience with that of three friends whom she met when having surgery and who provided
19 mutual support to each other, they suffered more than she. Even so, although she presented
20 as carrying on as normal through treatment, she was explicit that every facet of her life was
21 uncertain:
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32 I really don't know what will happen. I'd like to progress in life and maybe meet
33 somebody else or maybe stay with the person I'm with at the moment...just not getting ill
34 anymore.
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40 **Conditional 'Recovering: An Uncertain Future'**

41
42 Third interviews were conducted approximately 11/ 12 months following diagnosis, at which
43 point only two of the seven women interviewed had completed adjuvant treatment. Three
44 others had started five years preventive hormonal medication (Arimidex and Tamoxifen
45 respectively); and two women were beginning 12 months hospital based biological therapy
46 (Herceptin) involving three weekly infusions, alongside Tamoxifen. Although illness and
47 daily life work varied with their medical regimen, in contrast to previous interviews, all of
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3 them considered that life had changed irrevocably, albeit the precise lines of demarcation of
4
5 continuity and discontinuity were not fully drawn.
6

7 8 **“Another year out of my life”**

9
10 For women undergoing acute treatment, ‘illness’ work continued. Alongside persistent pain
11 and fatigue, new treatments produced different adverse effects, for example, joint pains from
12 combined biological therapies, and “*all engulfing*” hot flushes mimicking menopausal
13 symptoms commencing with Tamoxifen. Old and new symptoms were cumulative in their
14 physical impact, while the biological therapy regimen affected the rhythm of daily life. Even
15 so, they resumed some valued routines (for example, taking children to school; meeting
16 friends), albeit requiring ongoing assistance with practical tasks. As sequential treatments
17 stretched into the distance, the continued presence of cancer work engendered an overall
18 weariness and sense of loss for women at “*another year out of my life*”. Conflicting self-
19 concepts: “*not looking like me but feeling like me*” exacerbated the disparity between
20 appearance and experience. There was fear that however supportive close others, they were
21 tiring of living with the cancer, conveying that women should move beyond being a patient.
22 Yet, they felt as ‘patients’ whose lives were affected by illness and the acute treatment
23 regimen. Further, the shape of recovery was unknown, although there was discontinuity with
24 life before breast cancer.
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44 45 **Resuming ‘normal’?**

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47 Most women who had completed acute treatment talked about experiencing a gradual shift
48 toward recovering physical health. Pain and discomfort from treatment was receding; and
49 their presentation of self to the external world could pass as ‘healthy’ as their hair grew back
50 and other visible effects of adjuvant treatment (mouth ulcers, blotchy, dry skin) reduced. Yet
51 ‘normal’ had not resumed.
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3 In contrast to previous sub-phases when their expectation of recovery as ‘comeback’ to their
4 pre-diagnosis selves, their reference point for assessing ‘normal’ was how they felt during
5 treatment; not how they were pre-diagnosis:
6
7
8

9
10 I’ve settled really back to waking [in the night] three or four times...but unlike with
11 chemotherapy being awake for several hours, I’m not staying awake so I’ve come to
12 accept that as normal for me.
13
14
15

16
17 Body failure presenting as fatigue, limited capacity for activity at times. More than usual
18 pacing, life itself had slowed down.
19
20

21
22 I feel I have to lie down because I feel so lethargic...I can’t think straight either.
23

24
25 Despite re-establishing a pattern of daily life routines, elapsed time increased the chasm
26 between the person they were before and now and they conveyed a sense of disjuncture
27 between their previous and current lives. In part, this reflected the impact of illness time on
28 significant life stage transitions.
29
30
31
32

33
34 Even as illness and its management seemed to collapse time, women’s social world had not
35 stood still. For those who were planning to retire, illness meant that they missed the symbolic
36 markers of an orderly transition from work (for example, the ‘leaving do’) so that it felt
37 unreal. For women in the later years of paid working lives and who had regarded work as a
38 valued source of self-worth, illness precipitated early retirement, a permanent disruption in
39 life routines. One woman’s account illustrates the interplay between time and altered social
40 worlds:
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49
50 I held on to thinking that life will be as normal. I will get through this and I will go
51 back to work and we will carry on as we did before this happened. But ... I came to the
52 decision that no, life isn’t going to be the same. I’ve handed my notice in, and we are
53 going to do lots of things, without work coming into it... I didn’t want to give it up...it
54
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2
3 was a big part of my life but I'd gone back ...and it didn't have that same pull ... It felt
4
5 different, a lot of new faces, and I thought did I really want to come back and start
6
7 again.
8
9

10 Among older women, illness contributed to a re-appraisal of them as 'old': was it
11
12 chronological age that explained being poorly and not the cancer? One woman expressed it
13
14 thus:
15
16

17 I don't think I will even be back to the way I used to be with the stiffness and
18
19 tiredness...is it getting old? It's over a year since this first happened and it's added a
20
21 year on to my life so maybe it is part of getting old as well....I get annoyed with the
22
23 way I am because I'm slower and it's difficult to relate to that because I shouldn't think
24
25 of 63 as being old.
26
27

28 As well as 'doing' different, a key aspect of 'being' different from before was the shift that
29
30 had taken place in their future orientation. Now, they articulated hesitancy about looking too
31
32 far ahead. The failure of the body to signify life threatening illness, which was a source of
33
34 worry after diagnosis, moved center-stage. Every pain, lump and discomfort assumed new
35
36 meaning when appraised through the cancer lens: is it indicative of cancer?
37
38

39 Although ontological insecurity touched everyone, the nature of their cancer experience
40
41 shaped its depth and pervasiveness. At one end of the spectrum was a woman who alone
42
43 among those interviewed resumed previous life routines, returning to work after treatment.
44
45 She spoke of heightened sensitivity to aches and pains that might indicate cancer, yet felt
46
47 optimistic about the future and was planning to move to a more expensive house. At the
48
49 opposite end of the spectrum, were women whose insecurity was exacerbated on account of
50
51 unanticipated contingencies. Shortly after completing chemotherapy, the sister of one
52
53 participant, who had provided practical and emotional support, was diagnosed with, and died
54
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1
2
3 of lung cancer within four months. She described feeling bereft as a consequence, hated her
4
5 body and fear of the cancer returning was ever present.
6

7
8 I go to bed thinking it's going to come somewhere else...especially when my sister
9
10 died. And my partner...he gets it. He will say: "I'm not going to lose you...don't think
11
12 like that". But I do. I don't know why he is still here. I keep pushing him away. But
13
14 he says I'm not going anywhere.
15

16
17 Between these extremes, women, who because of multiple treatments or the nature of their
18
19 cancer and severity of treatment effects, were more circumspect about thinking too far into
20
21 the future. Several recounted being told that their tumor was 'aggressive' around the time
22
23 of their diagnosis and continued to ruminate on these words. For them, the possibility of
24
25 cancer returning was not a generalized fear, it was a real possibility, and contributed to
26
27 continued emotionality.
28
29

30
31 During the interview, women wept quietly as they reflected back on their experience.
32
33 Several commented that the interview allowed them to express emotions that they felt
34
35 unable to do with close others, not wanting "*to upset or burden them or show your*
36
37 *vulnerability*". Even those who reported ongoing emotional support from significant
38
39 others felt unable to fully share their future uncertainty.
40
41

42
43 I can't say that with certainty now [where life will take me]... whereas 12 months ago I
44
45 would have said yes...I try not to think about it too much. My husband, he won't hear
46
47 of it [cancer coming back] you are going to be fine and that is the end of it ... So there is
48
49 no point in pursuing it ... it may upset him as well so I wouldn't want to. And it's the
50
51 same with friends...I don't discuss it with them.
52

53
54 Women reprised the changes in their lives as a consequence of cancer with a mixture of pain
55
56 for what they had lost; pleasure in renewed value in the significance of personal relationships
57
58

1
2
3 and having time for themselves; and trepidation in face of an uncertain future. Their overall
4
5 presentation was that re-negotiating recovery was a work in progress; they still inhabited a
6
7 liminal space between illness and health (Little et al., 1998).
8
9

10 **Discussion and Conclusions**

11
12 Although the acute stage of breast cancer tends to extend considerably beyond in-hospital
13
14 care, the temporality of the illness experience as this unfolds over time has not been explored
15
16 in depth. We drew on concepts of 'trajectory' and 'illness work' developed from research on
17
18 chronic illness to examine how women made sense of, lived with and managed lives,
19
20 relationships and sense of self with breast cancer over the acute trajectory phase. We also
21
22 elected to convey women's accounts in the temporal order in which they were produced, so
23
24 that the messiness and chaos experienced particularly in the early sub-phases of the acute
25
26 trajectory were visible.
27
28

29
30 For women in this study, the acute breast cancer trajectory comprised of several sub-phases.
31
32 Each sub-phase represented the distinctive context in which illness management took place
33
34 and required work on the part of women and significant others to manage the practical,
35
36 emotional, relational and existential demands of an illness that intruded every aspect of their
37
38 lives.
39
40

41
42 The distinctiveness of early breast cancer, in comparison with other acute and chronic
43
44 conditions, was that it was revealed as an 'illness' through a sequence of diagnostic tests.
45

46
47 The first sub-phase 'becoming a person with breast cancer' involved a journey characterised
48
49 by its speed and multiple encounters with medical professionals in which the probability of a
50
51 cancer diagnosis increased with each successive diagnostic procedure. The sense of rupture
52
53 of lives and selves consequent on the formal naming of the illness as cancer related to their
54
55 appraisal of cancer as a life threat. Unlike Blow et al.'s (2011) findings, diagnosis did not
56
57 begin a process of acceptance of breast cancer. Each subsequent trajectory sub-phase opened
58

1
2
3 up new sources of uncertainty about the trajectory projection and schema pertinent to disease
4
5 stage and treatment and involved the development of strategies to actively manage the illness.
6
7

8 The presentation of selves and lives as 'normal' following surgical treatment and
9
10 subsequently, co-existed with a profound sense of disruption. Differentiating between
11
12 'doing', 'relating' and 'being' normal highlighted the work engaged in by women in different
13
14 acute sub-phases to sustain hope in the possibility of recovery. It provided insight into the
15
16 way in which the structural and dynamic character of the illness and treatment regimen
17
18 ('structure in process') affected the extent to which women were able to maintain continuity
19
20 with their behavioural, emotional, relational and embodied selves. It enabled exploration of
21
22 the dissonance between women's experience of early breast cancer and their presentation or
23
24 narratives of it to understand the context in which such accounts are formed (Bury, 2001;
25
26 Reissman, 2015).
27
28
29

30 For women in our study, performance of 'normal' in the sense of 'doing' and 'relating'
31
32 normal was a pre-eminent thread in protecting their sense of self as they proceeded through
33
34 the first steps in treatment. It did not denote denial of the cancer diagnosis; but was
35
36 supportive of, and a means of taking control of recovery. In this, women expressed and
37
38 conveyed common socio-cultural understandings of cancer: that they had to share
39
40 responsibility in managing the illness and that 'beating the cancer' required a positive stance.
41
42 The cultural dominance of these understandings has been demonstrated through multiple
43
44 routes: in representations of cancer in the media (Seale, 2002; Clarke & Everest, 2006); as
45
46 extolled in bio-medical and professional discourse (Davis, 2008); and as a focus of a
47
48 particular style of research (Wilkinson & Kitzinger, 2000).
49
50
51
52

53 It was the struggle to sustain positivity that informed the emotion work which assumed such
54
55 significance across the acute trajectory, albeit taking different forms in each sub-phase. For
56
57
58

1
2
3 women and significant others, the diagnosis of cancer and changes in lives, relationships and
4
5 sense of self wrought by the life threat resulted in intense emotion - fear, distress, sadness,
6
7 actual and anticipatory loss. Open expression of emotion by women and 'significant others'
8
9 threatened to dent the appearance of positivity. Presenting as 'strong' and suppressing
10
11 'vulnerability' involved considerable work, not only by women, but by close family and
12
13 friends. Emotion work took explicit form where women enjoined close others to be
14
15 'positive': "*you do your crying before or after you come to see me*". More commonly, there
16
17 existed a shared, unspoken understanding that emotion work was a reciprocal process.
18
19

20
21 There is an uneasy fit between the nature of emotion work here and Hochschild's (1983)
22
23 theory of emotional work, emotional labor and emotion management. Seeking to explain
24
25 how expression of feelings are no less orderly and shaped by social rules as behavior and
26
27 action, Hochschild distinguishes between emotional labor as the management of feeling to
28
29 create a 'publicly observable facial and bodily display' and emotional work, to the same acts
30
31 carried out in the private sphere. In both spheres, emotion management is what people do to
32
33 regulate their own emotions in ways that are judged appropriate to the situation; most
34
35 research focusing on emotional labor.
36
37

38
39 In context of early breast cancer, several features of emotion work that women (and close
40
41 others) engaged in, suggest that application of 'feeling rules' neither captures the depth of the
42
43 conflicting emotions women were struggling with, nor the complexity of the work involved.
44
45 First, women were simultaneously grappling with multiple and contradictory emotions which
46
47 were deeply felt. Although emotion management was directed interactively at enhancing the
48
49 positive, distress and loss found expression when alone. Second, women's heightened
50
51 emotionality meant that feelings bubbled up uncontrollably which in turn threatened to
52
53 undermine the work on, for and with close others to convey positivity. The conception of
54
55 rationality and control underpinning the operation of feeling rules sits uneasily with this kind
56
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58

1
2
3 of emotion work. Third, emotion work was a reciprocal and mutual endeavor involving
4 women and significant others; it was work in relation on and for selves vis a vis others.
5
6
7 Significant others were not only mobilized to support the work of 'normalization' to sustain
8
9
10 positivity but they also embraced it.

11
12 Other studies of cancer have referred to the process of 'normalization' or 'normalizing'
13
14 patient experience of illness. Hilton (1996) from interviews with families and women with
15
16 early breast cancer, conceptualized 'normalization' as both a style of coping and a marker of
17
18 recovery such that 'getting back to normal' and resuming everyday life was 'putting the
19
20 cancer behind them'. Normalization strategies included minimizing disruptiveness, de-
21
22 emphasizing or minimizing role changes and demands and reframing negatives to be more
23
24 positive. 'Getting back to normal' was perceived as possible in context of the acute nature of
25
26 early breast cancer; illness had an end point when treatment effects subsided. Further,
27
28 'normalization' was reported as most effective where symptoms had less impact and were
29
30 less intrusive, so that maintaining or resuming 'normal' patterns were possible. The findings
31
32 primarily conveyed the voices of family members, perhaps contributing to the conception of
33
34 'normalization' as being the end of the acute phase and point of recovery. Similarly, in their
35
36 study of wives of patients with prostate cancer (Williams et al., 2014), the authors considered
37
38 that the 'normalization' narrative conveyed by wives was an expression of 'benevolent
39
40 concealment': women underplayed their own distress, engaging with their spouses' problems
41
42 and not their own. They concluded that 'normalization' pursued by wives conferred dis-
43
44
45
46
47
48 benefits for them.

49
50 Although our study only involved interviews with women, significant others were visible as
51
52 key characters in the acute breast cancer trajectory, implicated in, and contributing to the
53
54 different lines of work involved. Even as the trajectory was experienced as a relational
55
56 enterprise, women kept their deepest fears and future uncertainty to themselves not wanting
57
58

1
2
3 to burden close family and friends. They also acknowledged that close others were similarly
4 engaged in reciprocal protection, a process that Lindholm et al. (2002), focusing on the dis-
5 benefits, referred to as the "*vicious circle of mutual protection*" (p. 251). What these different
6 studies point to is the need to explore the reciprocal nature of cancer 'illness' work and the
7 relative benefits and dis-benefits over different trajectory phases.
8
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13
14 Closer scrutiny of the work to sustain 'normal' highlights the need to go beyond individual
15 narratives to locate them in context and purpose (Bury, 2002). Women's accounts of 'doing',
16 'relating' and 'being' normal in this research suggested different purposes (and associated
17 work) at different sub-phases of the acute trajectory. Moreover, although these dimensions
18 of normalization were inter-related, disruption to usual activities for example could be
19 rationalized as temporary and one's self-concept as unchanged sustained i.e. 'normalization'
20 assumed non-linear and interactive forms. It was shaped by the contingencies of the illness
21 and treatment regimen, and their impact over time on women and significant others. It
22 involved costs as well as benefits (Knafl & Deatruck, 1986; Robinson, 1993). For some
23 women, the struggle to sustain hope by holding on to 'doing' and 'relating' normal,
24 contributed to tensions in close relationships, increasing their isolation and sense of being
25 unsupported. There were also intimations that women were ambiguous about
26 'normalization' and 'keeping positive' as effective in securing recovery. For most women,
27 there were significant turning points. The narrative of 'normal' broke down during adjuvant
28 treatment: 'doing' and 'being' normal were unsustainable with intrusive symptoms. This also
29 placed at risk 'relating' as normal with significant others: women did not want to burden
30 them with their pain and fears for the future. The conclusion of treatment represented another
31 turning point. Women's sense of self had altered; with one exception, they were still in
32 process of 'becoming' and recovery was incomplete.
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3 The concept of ‘uncertainty’ has emerged as a key theme in the breast cancer survivorship
4 literature (Thomas-MacLean, 2004; McKenzie & Crouch, 2004; Thomas-MacLean, 2004;
5 Powers et al., 2016; Trusson et al., 2016). Theories of uncertainty in illness, particularly
6 drawing on broader psychological theories (Mishel, 1988, 1990, 1997), have been subject of
7 considerable research interest. Thus, Mishel defines uncertainty as the inability to attribute
8 meaning to illness-related events and to accurately predict outcomes on account of disease
9 complexity, poor information and the unpredictability or ambiguity of such events.
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Uncertainty then is embedded in illness events that have those characteristics. She argues that uncertainty is a neutral cognitive state and it is the person’s appraisal and response to uncertainty that mediates its impact. Although the distinction between uncertainty as a cognitive state and how it is appraised is a useful heuristic, it is difficult to differentiate them in practice. Thus the sense of rupture of lives and selves consequent on the formal naming of the illness as cancer related to women’s appraisal of cancer as a life threat.

In this study, uncertainty regarding the nature of their illness and the future, featured over the whole acute trajectory, although the sources of uncertainty and how these were appraised and responded to varied between sub-phases. At each sub-phase, women anticipated new challenges arising as they simultaneously sought to manage the immediate lived demands of illness and impact of treatment for a condition that posed a future life threat. The primary strategy they adopted in the early trajectory sub-phases was controlling negative emotions – ‘being’, ‘doing’ and ‘relating’ normal to sustain positivity. They tended to downplay current and anticipatory fears as the diagnosis challenged what was taken-for-granted in terms of an ongoing life. The struggle to maintain some control over lives and selves in conditions of emotional turmoil also contributed to the difficulties experienced in seeking out and accepting support (formal and informal). Although seeking information, particularly ‘expert’ information has been identified as a primary means for reducing uncertainty (Mishel 1988),

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3 for women here in context of breast cancer it assumed less importance. In part, this reflected
4 their perception of the unpredictability of an illness that varied in its intrusiveness when
5 diagnosed, in the responsiveness of individuals to treatment and in the severity of symptoms
6 experienced. They distrusted certainty even as they hoped for it. For women who had
7 completed treatment, the meaning and significance of ‘uncertainty’ varied with their
8 experience of illness and their conception of the trajectory projection – from a generalized
9 anxiety about recurrence to more specific assessment of actual risk for individuals.
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11 An important feature of the study was the methodology adopted: multiple qualitative
12 interviews aimed at providing a contemporaneous account of the emergent meaning of the
13 illness and the associated work of managing it as these evolved in time. This meant we were
14 able to access emotions and experience close to the events to which they pertained and which
15 gave rise to them and draw out deeper understanding of the process of the impact and coping
16 with breast cancer in context of women’s everyday lifeworld. Even so, the length and
17 complexity of the acute trajectory meant that more than 12 months following diagnosis,
18 several women were entering a new phase of acute treatment and most of the remainder were
19 prescribed preventive medication. Exploration of the acute trajectory in its entirety therefore
20 represents a major research gap.
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22 The study has several implications for practice. It draws attention to variation in the needs
23 and concerns of women across different sub-phases of the acute breast cancer trajectory,
24 particularly given the speed of diagnosis and commencement of treatment. While specific
25 sub-phases (diagnosis and adjuvant therapy) are recognized as ‘turning points’ for resource
26 investment, these are also the sub-phases during which women experience heightened
27 emotionality simultaneously with ‘keeping positive’ and which make it difficult for them to
28 reach out and receive emotional help. During these sub-phases, peer support from women
29 who have gone through the experience may be more acceptable. Our findings suggest that
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3 during the immediate post-treatment period when women are beginning to come to terms
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5 with the changes in their lives as a consequence of a cancer diagnosis, they may be more
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7 open to accepting support. Yet this is often when services and support withdraw. Finally, for
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9 professionals, our study points to the significance of seeing and working with the person
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11 with cancer and their significant others relationally; although managing the complexity of
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13 processes of mutual protection in context of a perceived life threat, requires particular
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15 sensitivities and skill.
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18 19 **LIMITATIONS**

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21 The study was conducted among a small sample of women. Intended to elicit understanding
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23 of the acute breast cancer trajectory, this was not fully accomplished. The variability of the
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25 treatment regimen meant that over 12 months we could not explore the totality of the acute
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27 phase for all participants. It is possible that following through the acute trajectory to the end
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29 would have required further elaboration and refinement of its sub-phases. The third set of
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31 interviews was carried out only with a sub-sample. Although these were selected
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33 theoretically to explore the impact of different treatment regimens and life stages on meaning
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35 and action, the findings posed new questions we were unable to answer, for example, the
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37 reciprocal relationship between a life-threatening illness and self-concept as 'old'.
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41 Other aspects of the findings provide clues about the impact of different sets of contingencies
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43 on the overall trajectory projection, for example those relating to the disease course and
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45 treatment response. For example, it is possible that Vera's negative reaction to treatment, her
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47 multiple co-morbidities and subsequent stroke initiated an unstable, deteriorating or dying
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49 trajectory phase. How such a shift between trajectory phases might have impacted on
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51 meaning, action and interaction would offer insight into the process of transition over the
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53 breast cancer trajectory as a whole with implications for theoretical understanding and
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practice. Similarly, another set of contingencies with likely impact on the experience and management of illness are major changes in social relationships and networks. Although research suggests little change in relationship status as a consequence of cancer, the impact of the dis-benefits of ‘normalization’ and the ‘vicious circle of mutual protection’ on relationships, requires further study.

For Peer Review

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