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 Chronic Illness

'An interpretative phenomenological analysis of the meaning of work to women living with breast cancer'.

Journal:	<i>Chronic Illness</i>
Manuscript ID	CHI-19-0090.R2
Manuscript Type:	Original Article
Keywords:	Cancer, Supportive care, Information needs, Work, Interpretative Phenomenological Analysis
Abstract:	<p>Objective: Work is an important aspect of everyday life. This remains true for those living with and beyond cancer. Less is known about how the meaning of work may change over the cancer journey, the needs of the individual in response to changes and how healthcare professionals and employing organisations can meet these needs. The aim of this study was to explore the lived experience of work after treatment for breast cancer in a group of professional working women within the UK.</p> <p>Methods: This article presents an Interpretative Phenomenological Analysis (IPA) of the experiences of 15 professional women diagnosed with breast cancer.</p> <p>Results: We discuss these women's journey from 1) rethinking the meaning of work to 2) making decisions about work ability and advice on work to 3) transitioning back in to the workplace and the value of continued engagement with employer.</p> <p>Discussion: The findings from this study demonstrate the complex interplay between living with cancer, treatment decisions and work. This study highlights two key areas for inclusion in practice: 1) support from Healthcare Professionals and judgements of functional ability and work ability and 2) the role of line managers in managing cancer and work.</p>

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Introduction:

~~Most~~ The majority of breast cancer cases occur among women of working-age and older [1]. Despite this, there is a lack of research that directly examines the role of ~~the~~ key stakeholders (individuals, health care professionals (HCPs) and key individuals within organisations) and the interplay over time between diagnosis and treatment (decisions and experience), individual adaptation and organisational accommodations for working women diagnosed with breast cancer.

In providing an overview of existing literature, it is important to acknowledge ~~that~~ different levels of focus e.g. type of cancer, type of question related to work, type of methods used, geographical context and key stakeholder groups. There is an established literature around the experience of being diagnosed with a cancer and around individual and organisational perspectives on the management of, engagement with and return to work (2–7). A smaller set of studies have focused solely on women diagnosed with breast cancer. Few studies have looked at the role of ~~health care professionals~~ HCPs in women's return to work following a diagnosis ~~of cancer~~ (2,8–12). Little has been done on the combined role of different stakeholders on individual adaptation, supportive care ~~(HCP)~~ and organisational behaviour from point of diagnosis onwards.

Often, diagnostic and treatment protocols omit discussion and advice on work engagement while discussions at work around breast cancer can prove challenging. Most of the broadly relevant studies have ~~either~~ taken a medical perspective on diagnosis and treatment and failed to include work engagement and employment status(13–15) as important factors in a persons' cancer journey. One possible outcome is that critical decisions around treatment, care and working life are uninformed, unsupported and often poorly made.

The larger focus has been on assessment of return-to-work, absenteeism, work disability and the financial consequences following diagnosis of breast cancer without due consideration of the role of supportive care and appropriateness of decisions around readiness and functional ability (16–23). An underlying struggle to resolve competition between cancer and economic survival may influence the decisions women make about work and readiness and ability to return to work. Less is known about how the meaning of work may change over the cancer

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3 journey and what the needs of the individual may be in response to any changes and how
4 [healthcare professional HCPs](#) and employing organisations contribute to meeting the needs
5 of the individual (16,24,25).
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10 The aim of this study was to explore these issues by focusing on the lived experience of work
11 after a breast cancer diagnosis and treatment amongst a group of professional working
12 women within the UK.
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16 17 18 **Methods**

19 This is a qualitative study with 15 women who took part in semi-structured interviews
20 exploring their experience of work engagement and breast cancer. Interview transcripts were
21 subjected to IPA and the study followed the procedures of IPA as elucidated in Smith *et al*
22 (26). IPA is an experiential approach whose epistemological underpinnings are rooted in
23 phenomenological philosophy and hermeneutic theory. This dual focus speaks to IPA's
24 commitment to understanding the lived first hand world that we are immersed in and which
25 is lived, felt, understood and made sense of by a conscious actor (See (27)_for further
26 discussion of IPA principles).
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36 A varied research team aims to advance the transference of knowledge across health related
37 disciplines. The first three authors have a wide range of experience in health and occupational
38 health psychology and the fourth author is a university based qualitative researcher with
39 expertise in phenomenological approaches, predominantly IPA. During the project, the team
40 worked closely with a consultant oncologist specialising in breast cancer.
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47 *Participants and data collection*

48 39 professional (as defined by occupational classification) working women with breast cancer
49 were invited to participate in this study during a routine consultation at [blinded - a hospital
50 in the UK]. Eligibility criteria included native British women who: had received a diagnosis of
51 primary breast cancer within the last five years; who were receiving or had received
52 treatment for breast cancer; were aged between 30 and 60 years old; were working at the
53 time of diagnosis, and; were in a professional occupation. Those who expressed an interest
54 met with one of the research team to discuss the study in more detail. A study information
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3 pack (letter of invitation, participant information sheet, consent form, and short demographic
4 questionnaire) was given to interested parties. Women were asked to contact the research
5 team to confirm whether they wished to participate within 14 days of invitation. See Table 1
6 for participant information.
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12 [INSERT TABLE 1]
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16 *Interviews*

17 In-depth qualitative interviews were conducted with participants, either face-to-face or over
18 the telephone. Both options were offered to each participant to fit around their medical and
19 general life commitments and their work. There was no difference between the length of time
20 women spoke for or the richness of the data gathered using the two approaches. The
21 interviews commenced with an open question inviting women to share their experience of
22 being diagnosed with breast cancer, and how they managed work and their working lives
23 thereafter. The interviews were designed to obtain women's experiences of breast cancer in
24 relation to their knowledge of, and decisions on, work participation and cancer treatment,
25 and to explore meaning attributed to such experiences in their cultural, psychosocial, work,
26 and medical contexts. All interviews were audio-recorded and transcribed verbatim with an
27 average time of 94 minutes. All participants were told that they could terminate their
28 interview at any time. Nobody terminated their interview early. Written or verbal consent
29 was obtained from all participants and recorded.
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43 *Data Analysis*

44 The principles and analytic steps of IPA are well documented and accessible (26,27). In brief,
45 this includes reading and re-reading each transcript to allow immersion in the data before
46 making initial notes which reflect participants' concerns which show up as things to be
47 reflected on and made sense of. Initial noting ranges from descriptive comments to noting
48 linguistic elements such as metaphor as well as recording well-as-noting any early
49 interpretative thinking. Through a reflective engagement-and-'dwelling', these exploratory
50 notes are combined, collapsed and transformed into emergent themes which are
51 subsequently clustered based on conceptual similarities. The end result is a thematic
52 structure for each participant which captures the most salient experiential dimensions for
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3 them. These idiographic analyses are then examined for convergence and divergence and a
4 final thematic structure created which represents both shared and idiosyncratic features for
5 all participants. This structure provides the scaffolding for the subsequent analytic narrative.
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10 What is sometimes missing is a sense of how these steps are put into action and realised in
11 the research. Limitations of space preclude any detailed description of this –but included:
12 adopting a stance of “concernful involvement” (28) ~~throughout~~ which recognizes that both
13 ~~the~~ participant and ~~the~~ researcher are involved in ~~reflecting and~~ making sense of a world in
14 which people, objects and events *-matter*; reminding ourselves that the steps of IPA are asking
15 us to turn away from *facts* to *meanings* through the reflective process. In the early stages we
16 worked independently being open to possible meanings and keeping emergent themes open
17 and provisional. As we moved through the steps, we held several discussions where we
18 reflected on this early sense-making, moving in an iterative fashion between the transcript
19 and emergent themes. The final set of themes was reviewed and determined by all members
20 of the research team.
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31 32 *Study Permissions*

33 Ethical permission was granted by the NHS East of Scotland Research Ethics Committee (Ref
34 No. 15/ES/0177). NHS Research and Development (R&D) permission was granted by NHS
35 Grampian (Reference Number: 2015UA016).
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41 42 **Findings**

43 Four main themes were revealed using IPA analysis. It was evident throughout all ~~of the key~~
44 themes that their health was the priority for all the women interviewed. At the same time,
45 work remained an important concern for them ~~all of these women~~.
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51 The first theme illustrated how a cancer diagnosis was a distressing experience for these ~~is~~
52 ~~sample of~~ professional women. They used words such as ‘frightening’, ‘devastating’ and
53 ‘surreal’ to convey how they felt about their situation. The nature of their experience is made
54 evident in the existing literature (e.g. (29–31) and therefore we concentrate in this paper on
55 the other three ~~two~~ novel themes that focused on the complex dynamic between living with
56 the reality of cancer, its treatment and work engagement.
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5 The first of these ~~three-novel~~ themes addressed the *changing meaning of work* for the women
6 involved and is the more existential in nature emphasising issues of relationality and selfhood.
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8 The second of the two novel themes described how more 'concrete' issues such as the advice
9 and support available in relation to return to work and judgements of readiness and
10 functional ability and work ability. The third theme illustrated the role of employers in
11 women's experience of working. This described how employers behaviour impacted on the
12 women involved and shaped their decisions not only to work but also how to manage the
13 nature of work.
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20 21 **Theme 1: "Why would I do all of this again? What should I do now?" Rethinking the meaning** 22 **of work**

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24 The professional women interviewed expressed a variety of views about the meaning of work
25 following a diagnosis of cancer. These views appeared to be fluid and over the course of time
26 since diagnosis were modified in response to factors such as the attitudes of their ~~healthcare~~
27 ~~professionals~~HCPs, employers and work colleagues. The views of both ~~healthcare~~
28 ~~professional~~HCPs and employers were important in this consideration of the meaning of work
29 and women's understanding of their abilities and limitations. In particular, these views
30 reflected a tension between wanting to say positive things about treatment, work, and their
31 employers and describing negative experiences and events around supportive care,
32 information and work.
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43 Prior to being diagnosed with cancer, work was valued by ~~the our sample of professional~~
44 women and shaped a significant part of their identity. This persisted for only three of the
45 women across their cancer journey as exemplified by Helen:
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51 "I still need to work ... I need to have a little bit of something meaningful outside of
52 home life and the family". (Helen, ~~Healthcare Worker~~)
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56 Work also appeared important, in part, because it enabled these women to feel that they
57 were coping and that their lives were returning to normal:
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3 “Going back to work was almost in some ways burying my head in the sand ... this
4 wasn’t happening to me ... work was me back at normality again. Returning to work
5 was a coping mechanism”. (Sam, ~~Healthcare Worker~~)
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10 However, on returning to work after cancer treatment, twelve of the women felt less engaged
11 with their job and with their work. This loss of engagement appeared associated with a
12 number of individual factors including, for example, their re-evaluation and rebalancing of
13 priorities and increased emphasis on self and work-life balance. Their illness provided room
14 for reflection on the value of work overall and its place in their lives:
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21 “I just kept thinking if my cancer comes back and I’m working like this, I’m not going
22 to be happy ... I’ll die unhappy”. (Anna, ~~Business and Research Professional~~)
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27 At the same time, a sense of loss over the diminished importance of work was felt by others;
28 the cancer had forced a change and left them feeling uncertain and somewhat redundant:
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32 “It’s still in my mind that I’m not, I’m not there, that ‘there’ is not my future anymore.”
33 (Louise, ~~Education Professional~~)
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38 As a result of their changing perceptions about work ~~having been diagnosed with cancer~~, all
39 the women interviewed contemplated changing their roles or careers or taking early
40 retirement. There were some who acted on this and who had already changed their jobs or
41 profession.
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47 “I’ve got a part-time job now ... No stress, nothing, and that’s what I needed ... I want
48 to be happy in life without the worry and stress of something else ... I do know that if
49 I hadn’t had the cancer, I would still be working in my old job”. (Anna, ~~Business,~~
50 ~~Research Professional~~)
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56 Anna reflected on how having been diagnosed with cancer had disrupted and transformed
57 her approach to work. As a result of her diagnosis, any job that she takes on in the future will
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3 have to match a new set of expectations and be stress and responsibility free. In contrast,
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5 Fiona's wish to reduce job-related stress was achieved through a plan to move sideways:
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9 "I still wanted to work in a similar area ... It is clear-cut and doable ... but I just felt
10 there could be less stress in a new job... I didn't want the stress of starting to learn a
11 whole new job with a whole set of new skills ... a sideways move in the same kind of
12 area, I think is what I needed to do." (Fiona, ~~Public Services Professional~~)
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18 For these women, returning to their old job did not feel possible and they revised their
19 expectations of what sort of work they wanted to do. The main driver of such decisions
20 appeared to be reducing work-related stress. A career, as opposed to working, became less
21 important after being diagnosed with cancer. This is perhaps somewhat surprising among this
22 sample of professional women, many of whom had worked hard to obtain a high-level of
23 achievement in their job.
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31 "Life's too short and you ... this isn't really where you thought you would be career-
32 wise at this point in time. This isn't quite how it was meant to be ... you need to take
33 stock and stop". (Maggie, ~~Business Professional~~)
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38 Maggie's observations highlight how significant health-related events such as diagnosis and
39 treatment of cancer can derail not only one's established goals but the overall *taken-for-*
40 *granted* trajectory of life. The seemingly trite comment that *life is too short* is anything but.
41 Rather it emphasises the need for clearly defined support for people navigating the complex
42 and longer term dynamic of work and cancer and who have been forced to face their
43 vulnerability and recognise their mortality.
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51 This ~~is second-first~~ theme illustrates how having a diagnosis of cancer impacted on how the
52 ~~professional women in the sample~~ thought about work and careers and their meaning as
53 result of being diagnosed with cancer. Two contrasting lines of thought were obvious in their
54 reports. The first was that having breast cancer and dealing with it required them to change
55 the importance that they placed on their work and careers reducing the demands and stress
56 that they placed on them so that they could better cope with having cancer and with its
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3 treatment. The second was that continuing to work would offer a distraction from cancer and
4 help them maintain some sort of normality especially leading up to treatment. Of course,
5 these two lines of thought were not mutually exclusive and could change across their cancer
6 journey.
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10 11 12 **Theme 2: “You decide. It’s entirely up to you” Making decisions about work ability and** 13 **taking advice on work.** 14 15

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18 The changing meaning of work appeared intimately entwined with decisions about when and
19 how to work including the questions whether to work on following their diagnosis and, if not,
20 when to return to work. At diagnosis, ~~most the majority~~ of ~~the~~ women ~~in the sample~~ decided
21 to stay off work for the duration of their treatment. They reported feeling that they would
22 not be able to cope with combining the responsibilities of work with cancer treatment. By
23 staying off work, women believed that they would allow themselves time and space to adjust
24 to the diagnosis and focus on their health.
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32 ~~“I had no intention of attempting to work during chemotherapy as I didn’t find that~~
33 ~~was the biggest priority in my particular situation. I wanted to focus on my health”.~~
34 ~~(Rachel, Education Professional)~~
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40 “... work was becoming far too much for me ... I was coming to work trying to be really
41 all things for all people ... eventually I was like “Actually I can’t do this” ... I wanted to
42 put myself and planning first. I wanted to ... make sure I had food in my freezer so if I
43 wasn’t able to cook I would have that... I must do all these things before my surgery
44 ...”. (Sophie, ~~Protective Services Professional~~)
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51 Three women chose to continue working up until the point of ~~breast cancer~~ surgery. Work
52 appeared to provide the ~~emese women~~ with a much needed distraction from ‘having cancer’
53 and gave them a sense of normality during this challenging period.
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3 “... when I was diagnosed ... I had about a month before my appointment for surgery
4 so ... I just went into work I just worked right up to then because I just felt I needed
5 to keep busy and keep my mind off it”. (Abby, ~~Business Professional~~)
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10 All of the women ~~in the sample~~ sought advice from healthcare providers regarding the
11 optimal time to return to work after radiotherapy or chemotherapy treatments were
12 completed. A common response from some primary and secondary providers appeared to
13 be “return to work when *you* feel ready”. Most professionals did make it clear that it was
14 important for the women not only to be *physically ready*, but also to *feel mentally strong*
15 *enough* to achieve a successful work return. While this approach was intended to be
16 supportive and give the person ownership of the issue, it was found challenging by some.
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25 *“I said to the [consultant] “You know ... Well, should I be going back to work now or
26 should I stay off?” and they said, “It’s entirely up to you. Entirely up to you. You decide.
27 It’s entirely up to you”.* (Maggie, ~~Business Professional~~)
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32 ~~“When I was having my treatment, I’d asked for a ballpark figure as to when I’d be
33 perhaps able to go back to work and both the breast nurse and the consultant had said
34 eight weeks would be fine. But, in my opinion, there was no way could I have ever
35 gone back after ... radiotherapy treatment ... after the initial five months...”.~~ (Helen,
36 ~~Healthcare Professional~~)
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43 Interestingly, three women in the sample reported feeling pressured to return to work earlier
44 than was recommended by their employers.
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49 *“It was like you were being cajoled into coming back to work by occupational health.
50 It’s about time you gave it a shot because you’ve been off long enough”.* (Louise,
51 ~~Education Professional~~)
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56 *“I felt a lot of pressure was put on me in terms of making decisions about work. I felt a
57 bit backed into a corner. I thought maybe I should just leave my job and look for
58 something I can cope with...”.* (Rachel, ~~Education Worker~~)
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5 In contrast, others ~~in the sample~~ were encouraged by their employers to return to work when
6 they felt ready to, which was informed by their managers' understanding or personal
7 experience of cancer.
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12 *"I felt I wasn't being pressured to return to work, that it was about me taking my time.*
13 *But I also thought that...because [my line manager] had had a diagnosis of breast*
14 *cancer that she did really understand..." (Eva, ~~Healthcare Professional~~)*
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20 The picture that this group of women painted regarding the advice that they were given about
21 decisions on work engagement and return to work from the different stakeholder groups
22 pointed up two important things. The first was that their ~~healthcare professional~~HCPs often
23 placed the key decisions with them – "you will know when you are ready" while most of the
24 women, at least initially, looked to the former for that decision. It appeared that they did not
25 always want to assume responsibility ~~for making that decision~~; highlighting ~~the importance of~~
26 ~~shared decision making~~ making that for these women, person-centred care meant working in
27 partnership and being given advice when it was needed to help navigate their identity as
28 patient and as worker. The second thing was that the advice ~~that~~ they received from their
29 employing organisation, including occupational health, was mixed. Where their senior
30 colleagues had some personal experience or understanding of cancer, they were felt to be
31 supportive and echo the advice given by the ~~healthcare professional~~HCPs; otherwise they
32 were felt to be less supportive sometimes to the point of appearing to 'bully' the women back
33 to work. This provides two clear recommendations for ~~healthcare professional~~HCPs and
34 employing organisations.
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49 **Theme 3: "Maybe just a little note ... to say how are you?" The value of continued**
50 **engagement with employer from point of diagnosis and of workplace support.**
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54 The third theme that ~~derive~~emerged from the analysis~~ed~~ concerned womens' experiences
55 when returning to work. These were grounded in the nature and strength of their
56 engagement with their employer and place of work from their diagnosis onwards. Those who
57 had maintained contact with their employer, in particular contact that was initiated and
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3 supported by the employer, tended to report more positive experiences of returning to work
4 than those who had not received any such engagement or support. This was focused at the
5 level of the immediate employer or line manager and may be grounded in trust and the social
6 processes of the work environment.
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12 Across the sample, contact and offers of support from the workplace varied during the
13 women's leave of absence with some women receiving much support while others received
14 little or ~~no~~ contact ~~and~~ support. This was believed, in some cases, to be related to
15 organisational or other workplace policies. Nevertheless, most women had expected their
16 employer to initiate some form of contact during their leave of absence and viewed lack of
17 contact negatively.
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25 *"... [during] the interim period when I had my treatment, um, I didn't hear anything*
26 *from work, very disappointing, quite upset that ... not that you want people to be*
27 *thinking about you and things like that but I just thought really maybe just a little note*
28 *or a letter or a text or something to say how are you? ... I didn't receive that so that*
29 *was a real disappointment". (Helen, Healthcare Worker)*
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36 Some women visited their workplace their leave of absence, which reduced some of their
37 fears about returning to work.
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42 *"... when I did go back to work ... it wasn't quite so scary as I had imagined because I*
43 *had been through the doors, I'd been up in the department, I'd seen a lot of the staff,*
44 *they were now completely aware of what was going on with me ... so I thought that*
45 *was a really good thing to have done...". (Emma, Education Worker)*
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51 The majority of women returned to work on a period of phased return following advice from
52 occupational health. This was seen as helpful as it allowed them to readjust to work within
53 their new capabilities and perspective.
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58 *"... it was a bit daunting having not worked for nine months, you know, just being*
59 *dotting around the house and then to be back at work, it was quite, um, tiring to begin*
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3 *with doing a full day ... it was useful having the phased return to sort of shorter days*
4 *until you work back up to speed..." (Abby, ~~Business Worker~~)*
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9 Many women received adequate support and work accommodations from their employer
10 following their diagnosis and treatment. This included emotional and practical support, such
11 as a phased return to work, reduced hours, and the provision of sick pay:
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16 *"... if there's a supportive environment at work ... from the start ... that kind of attitude*
17 *... then it's much easier to return". (Rachel, ~~Education Worker~~)*
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21 However, this was not the case for all of the women we spoke to. A few women highlighted
22 that their employer was not as supportive as they had expected them to be. This was
23 attributed largely to their lack of understanding about the impact of cancer diagnosis and
24 treatment and of the women's cancer journey. This ultimately led to difficulties for women in
25 being able to effectively engage with work.
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32 *"... when you go back to work ... even though people are listening to what has*
33 *happened to you ... they're still expecting that 100% or they think they are ... that's*
34 *something that you have to be aware of. I certainly have been surprised at that..."*
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38 *(Sam, ~~Healthcare Worker~~)*
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42 Many women were anxious about returning to work after cancer due to the often extended
43 period of sick leave, and initially they found it difficult to adapt to work. These women
44 reported that they struggled to concentrate at work and perform cognitive tasks whilst
45 managing fatigue and pain as a consequence of cancer treatment or their emotional resilience
46 had declined following their cancer experience.
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52 *~~"... I just find I can't cope with work ... I think I would if I hadn't had that trauma ... it's~~*
53 *~~not that just on its own in isolation, the breast cancer ... it was all the little bits that~~*
54 *~~have been added which haven't helped... You just haven't got that resilience behind you~~*
55 *~~anymore ... well, not to the same extent." (Fiona, ~~Social Services~~)~~*
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5 *"... it was a really difficult time [at work] ... and I think because I'd been there so long*
6 *everyone looked to me to keep things going it was useful to take that time out and*
7 *just realise that there's other people as capable as me so they can all just share the*
8 *load..."*. (Abby, ~~Business Professional~~)
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14 The contrasting experiences of the woman in this group demonstrate the complex interplay
15 between the women's ~~own~~ adjustment to their cancer diagnosis, ~~and~~ the changing meaning
16 of work, ~~their~~ readiness and ability to return to work and the behaviour of their employer
17 (grounded in their own understanding of cancer). It is also clear that there is an important
18 relational context with work colleagues in this meaning making. This further highlights the
19 importance of clear communication and understanding between all the key stakeholders in
20 the return to work process.
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29 Discussion

30 This study provides unique insight into the meaning of work following a cancer diagnosis for
31 professional working women living with breast cancer in Scotland. In particular, it allows for
32 a deeper understanding of the complex interplay between living with cancer, treatment and
33 related work decisions and how advice and support shaped their work engagement. These
34 findings are resonant with the current European and North American literature (e.g. (32,33)
35 and build our knowledge in this area.
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43 There was no prioritisation of work over health and treatment for these women. As might be
44 expected from the existing literature, work was clearly important ~~for them to these women~~
45 before their diagnosis of breast cancer (34,35) and this appears to be tied in with both the
46 meaning of work ~~forte~~ them and to their sense of identity. Cancer threatened their self-
47 identity and often led to a felt loss of control and, subsequently, to a search for the meaning
48 of work. ~~Many women reappraised the role of work in their lives after receiving a diagnosis~~
49 ~~of breast cancer.~~ While it is known that cancer can prompt a shift in priorities (16,33), the
50 novel finding here is the nuanced understanding of why and how. A key theme for the women
51 in this study was how the experienced loss of control led to a shift in identity and altered
52 priorities. This was grounded in the need to protect their self-identity, and to recover from
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3 feeling lost and diminished by their cancer. While work remained important to the majority
4 of women in this study, for psychological as well as financial reasons, many desired a better
5 work-life balance and way of working that would restore a sense of self and of control and
6 would allow a focus on new priorities. A change in meaning has been reported in previous
7 studies focused on change in work priorities and reduction / changes in working practice
8 (11,24,36). For the women in the current study, the change in meaning marked a shift from
9 pursuit of career and work as everything to self as important and work-life balance.
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18 The second novel finding is the issue of work ability being handed back to the women to make
19 a judgement and their feelings of not being prepared. Work ability has been much debated
20 and studied within the broader cancer literature (20,22,37,38) but there is little in terms of
21 how this judgement is made and whom this decision involves. The role of [HCPs Health Care](#)
22 [Professionals](#) has also been highlighted to a lesser extent (e.g. (8,39)) but with regards to
23 meeting information needs and appropriate discussion of work rather than around
24 judgements of work ability. Similarly, occupational health and occupational physicians have
25 been highlighted as key stakeholder groups within the delivery of return to work interventions
26 (e.g. (40)) and yet this study shows the negative impact of getting these decisions wrong and
27 women feeling additional pressure from occupational health providers. This highlights that
28 the importance of facilitating agreement between the individual, the health care provider and
29 the organisation about readiness and ability to return to work (9,22) [and also of achieving](#)
30 [non-tokenistic person-centred care](#).
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44 The third novel finding is the complex interplay between the individual level adaptation and
45 the behaviour of the employer. The literature focuses on the role of large organisations and
46 organisational behaviour (41) or the role of occupational health in making reasonable and
47 practicable accommodations as a minimum requirement (42). This is directed in the UK by the
48 Equalities Act (43). A highlighted gap in the literature is around what employers within
49 organisations should be doing beyond their legal duty of care and how to facilitate
50 implementation of recommendations (33,44–46). Current understanding within the cancer
51 literature is framed within the context of North American and Northern European
52 employment practices and healthcare systems (47–50). This study extended the debate
53 around employer behaviour and demonstrates the importance of the individual line
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3 manager's behaviour in determining the women's experience of return to work. Contact with
4 the individual line manager, rather than the organisation, while undergoing treatment was
5 felt to be a positive driver in remaining engaged with work. This allowed women to return to
6 the workplace while managing the cognitive, emotional and existential aspects of living with
7 and beyond breast cancer. This social contact, therefore, is a crucial element in the delivery
8 of accommodations at work that support the person's needs. Hakanen & Lindbohm (51) also
9 highlight the importance of social resources at work to support work engagement following
10 a diagnosis of cancer. Our findings ~~also~~ make clear the importance of realistic and supportive
11 advice given in relation to work and help provided in shaping work-related decisions across
12 the women's cancer journey. Clear consensus and guidance is a recommendation echoed
13 within the existing literature (11,20,25,34). It is also evident from our findings that there are
14 multiple aspects of the meaning of work, which include the psychosocial work environment,
15 that are important following a diagnosis of cancer. This requires further study.

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29 In turn, the findings do imply a need to provide line-managers, occupational health and HCPs
30 health care professionals with appropriate and up-to-date evidence-based knowledge and
31 training to ensure that they can provide information and advice. Despite being highlighted in
32 previous studies, there is still an acknowledged need for clear systems in place for the
33 exchange of information between these groups and other stakeholders (2,11,34).

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40 This study makes a strong contribution to knowledge. It is, however, important to recognise
41 the limitations of this work. As was the intention, this is grounded within a UK context. Given
42 the professional background of the women, ~~the access they had~~ to additional financial
43 resources may have influenced the decisions that they subsequently made about work. There
44 is a need to ~~develop this novel research and also to~~ explore the lived experiences of women
45 working in non-professional and insecure occupations, to understand the unique challenges
46 faced by this population. The interviews were conducted either face-to-face or by telephone
47 raising the question of whether the method used effected the data collected. The data from
48 the 15 participants were scrutinised to determine whether or not there were obvious and
49 substantive differences by method. None were detected.
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Conclusion

The findings from ~~this e-current~~ study demonstrate the complex interplay between living with cancer, treatment decisions and work. The goal of research in this area is to develop recommendations for health care and work-based practice to support working women with breast cancer in relation to work engagement, in the way in which they desire. ~~This e-current~~ study highlights two key areas for inclusion in practice: 1) support from ~~healthcare professionals~~ HCPs in managing the diagnosis of cancer and threats to self-identity and judgements of functional ability and work ability and 2) the role of others in managing cancer, treatment and work, in particular line managers ~~and key contacts~~ within the organisation.

Word count 4,995 excluding abstract, table and refs

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Table 1: Demographic characteristics

	Mean (SD) or n (%)
Age (years)	51.7 (5.3) Range 39-59
Marital Status	
Single	3 (20%)
Married or Civil Partnership	9 (60%)
Separated or Divorced	3 (20%)
Diagnosis	
Ductal Carcinoma in Situ (DCIS)	2 (13.3%)
Grade 1	2 (13.3%)
Grade 2	4 (26.7%)
Grade 3	6 (40.0%)
Missing	1 (6.7%)
Cancer treatment	
Lumpectomy	11 (73.3%)
Mastectomy	5 (33.3%)
Chemotherapy	8 (53.3%)
Radiotherapy	12 (80%)
Hormone Therapy	12 (80%)
Biological Therapy	1 (6.7%)
Educational Level	
Diploma/HND/HNC	7 (46.7%)
Bachelor's Degree	6 (40%)
Master's Degree	1 (6.7%)
Professional Degree	1 (6.7%)
Occupation*	
Healthcare	4 (26.7%)
Education	4 (26.7%)
Business and related research professionals	3 (20%)
Marketing and sales	1 (6.7%)
Protective services	1 (6.7%)
Public services	1 (6.7%)
Social services	1 (6.7%)
Work status at diagnosis	
Working full-time	6 (40.0%)
Working part-time	5 (33.3%)
Self-employed	1 (6.7%)
Work continuation during treatment	
Yes	2 (13.3%)
No	13 (86.7%)
Current work status	
Working full-time	6 (40%)
Working part-time	4 (26.7%)
Self-employed	1 (6.7%)

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Not currently working/on sick leave	3 (20%)
Retired	1 (6.7%)

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Introduction:

Most breast cancer cases occur among women of working-age and older [1]. Despite this, there is a lack of research that directly examines the role of key stakeholders (individuals, health care professionals (HCPs) and key individuals within organisations) and the interplay over time between diagnosis and treatment (decisions and experience), individual adaptation and organisational accommodations for working women diagnosed with breast cancer.

In providing an overview of existing literature, it is important to acknowledge different levels of focus e.g. type of cancer, type of question related to work, type of methods used, geographical context and key stakeholder groups. There is an established literature around the experience of being diagnosed with a cancer and around individual and organisational perspectives on the management of, engagement with and return to work (2–7). A smaller set of studies have focused solely on women diagnosed with breast cancer. Few studies have looked at the role of HCPs in women’s return to work following diagnosis (2,8–12). Little has been done on the combined role of different stakeholders on individual adaptation, supportive care and organisational behaviour from point of diagnosis onwards.

Often, diagnostic and treatment protocols omit discussion and advice on work engagement while discussions at work around breast cancer can prove challenging. Most of the broadly relevant studies have taken a medical perspective on diagnosis and treatment and failed to include work engagement and employment status(13–15) as important factors in a persons’ cancer journey. One possible outcome is that critical decisions around treatment, care and working life are uninformed, unsupported and often poorly made.

The larger focus has been on assessment of return-to-work, absenteeism, work disability and the financial consequences following diagnosis of breast cancer without due consideration of the role of supportive care and appropriateness of decisions around readiness and functional ability (16–23). An underlying struggle to resolve competition between cancer and economic survival may influence the decisions women make about work and readiness and ability to return to work. Less is known about how the meaning of work may change over the cancer journey and what the needs of the individual may be in response to any changes and how

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3 HCPs and employing organisations contribute to meeting the needs of the individual
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5 (16,24,25).
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9 The aim of this study was to explore these issues by focusing on the lived experience of work
10 after a breast cancer diagnosis and treatment amongst a group of professional working
11 women within the UK.
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15 16 **Methods**

17 This is a qualitative study with 15 women who took part in semi-structured interviews
18 exploring their experience of work engagement and breast cancer. Interview transcripts were
19 subjected to IPA and the study followed the procedures of IPA as elucidated in Smith *et al*
20 (26). IPA is an experiential approach whose epistemological underpinnings are rooted in
21 phenomenological philosophy and hermeneutic theory. This dual focus speaks to IPA's
22 commitment to understanding the lived first hand world that we are immersed in and which
23 is lived, felt, understood and made sense of by a conscious actor (See (27) for further
24 discussion of IPA principles).
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34 A varied research team aims to advance the transference of knowledge across health related
35 disciplines. The first three authors have a wide range of experience in health and occupational
36 health psychology and the fourth author is a university based qualitative researcher with
37 expertise in phenomenological approaches, predominantly IPA. During the project, the team
38 worked closely with a consultant oncologist specialising in breast cancer.
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45 *Participants and data collection*

46 39 professional (as defined by occupational classification) working women with breast cancer
47 were invited to participate in this study during a routine consultation at [blinded - a hospital
48 in the UK]. Eligibility criteria included native British women who: had received a diagnosis of
49 primary breast cancer within the last five years; who were receiving or had received
50 treatment for breast cancer; were aged between 30 and 60 years old; were working at the
51 time of diagnosis, and; were in a professional occupation. Those who expressed an interest
52 met with one of the research team to discuss the study in more detail. A study information
53 pack (letter of invitation, participant information sheet, consent form, and short demographic
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3 questionnaire) was given to interested parties. Women were asked to contact the research
4 team to confirm whether they wished to participate within 14 days of invitation. See Table 1
5 for participant information.
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10 [INSERT TABLE 1]
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14 *Interviews*

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16 In-depth qualitative interviews were conducted with participants, either face-to-face or over
17 the telephone. Both options were offered to each participant to fit around their medical and
18 general life commitments and their work. There was no difference between the length of time
19 women spoke for or the richness of the data gathered using the two approaches. The
20 interviews commenced with an open question inviting women to share their experience of
21 being diagnosed with breast cancer, and how they managed work and their working lives
22 thereafter. The interviews were designed to obtain women's experiences of breast cancer in
23 relation to their knowledge of, and decisions on, work participation and cancer treatment,
24 and to explore meaning attributed to such experiences in their cultural, psychosocial, work,
25 and medical contexts. All interviews were audio-recorded and transcribed verbatim with an
26 average time of 94 minutes. All participants were told that they could terminate their
27 interview at any time. Nobody terminated their interview early. Written or verbal consent
28 was obtained from all participants and recorded.
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41 *Data Analysis*

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43 The principles and analytic steps of IPA are well documented and accessible (26,27). In brief,
44 this includes reading and re-reading each transcript to allow immersion in the data before
45 making initial notes which reflect participants' concerns which show up as things to be
46 reflected on and made sense of. Initial noting ranges from descriptive comments to noting
47 linguistic elements such as metaphor as well as recording well any early interpretative
48 thinking. Through a reflective engagement, these exploratory notes are combined, collapsed
49 and transformed into emergent themes which are subsequently clustered based on
50 conceptual similarities. The end result is a thematic structure for each participant which
51 captures the most salient experiential dimensions for them. These idiographic analyses are
52 then examined for convergence and divergence and a final thematic structure created which
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3 represents both shared and idiosyncratic features for all participants. This structure provides
4 the scaffolding for the subsequent analytic narrative.
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9 What is sometimes missing is a sense of how these steps are put into action and realised in
10 the research. Limitations of space preclude any detailed description of this but included:
11 adopting a stance of “concernful involvement” (28) which recognizes that both participant
12 and researcher are involved in making sense of a world in which people, objects and events
13 *matter*; reminding ourselves that the steps of IPA are asking us to turn away from *facts* to
14 *meanings* through the reflective process. In the early stages we worked independently being
15 open to possible meanings and keeping emergent themes open and provisional. As we moved
16 through the steps, we held several discussions where we reflected on this early sense-making,
17 moving in an iterative fashion between the transcript and emergent themes. The final set of
18 themes was reviewed and determined by all members of the research team.
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29 *Study Permissions*

30 Ethical permission was granted by the NHS East of Scotland Research Ethics Committee (Ref
31 No. 15/ES/0177). NHS Research and Development (R&D) permission was granted by NHS
32 Grampian (Reference Number: 2015UA016).
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38 **Findings**

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40 Four main themes were revealed using IPA analysis. It was evident throughout all themes that
41 their health was the priority for all the women interviewed. At the same time, work remained
42 an important concern for them.
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47 The first theme illustrated how a cancer diagnosis was a distressing experience for these
48 professional women. They used words such as ‘frightening’, ‘devastating’ and ‘surreal’ to
49 convey how they felt about their situation. The nature of their experience is made evident in
50 the existing literature (e.g. (29–31) and therefore we concentrate in this paper on the other
51 three novel themes that focused on the complex dynamic between living with the reality of
52 cancer, its treatment and work engagement.
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3 The first of these novel themes addressed the *changing meaning of work* for the women
4 involved and is the more existential in nature emphasising issues of relationality and selfhood.
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6 The second of the two novel themes described how more ‘concrete’ issues such as the advice
7 and support available in relation to return to work and judgements of readiness and
8 functional ability and work ability. The third theme illustrated the role of employers in
9 women’s experience of working. This described how employers behaviour impacted on the
10 women involved and shaped their decisions not only to work but also how to manage the
11 nature of work.
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20 **Theme 1: “Why would I do all of this again? What should I do now?” Rethinking the meaning**
21 **of work**

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23 The professional women interviewed expressed a variety of views about the meaning of work
24 following a diagnosis of cancer. These views appeared to be fluid and over the course of time
25 were modified in response to factors such as the attitudes of their HCPs, employers and work
26 colleagues. The views of both HCPs and employers were important in this consideration of
27 the meaning of work and women’s understanding of their abilities and limitations. In
28 particular, these views reflected a tension between wanting to say positive things about
29 treatment, work, and their employers and describing negative experiences and events around
30 supportive care, information and work.
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40 Prior to being diagnosed with cancer, work was valued by the women and shaped a significant
41 part of their identity. This persisted for only three of the women across their cancer journey
42 as exemplified by Helen:
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47 “I still need to work ... I need to have a little bit of something meaningful outside of
48 home life and the family”. (Helen)
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52 Work also appeared important, in part, because it enabled these women to feel that they
53 were coping and that their lives were returning to normal:
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3 “Going back to work was almost in some ways burying my head in the sand ... this
4 wasn’t happening to me ... work was me back at normality again. Returning to work
5 was a coping mechanism”. (Sam)
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10 However, on returning to work after cancer treatment, twelve of the women felt less engaged
11 with their job and with their work. This loss of engagement appeared associated with a
12 number of individual factors including, for example, their re-evaluation and rebalancing of
13 priorities and increased emphasis on self and work-life balance. Their illness provided room
14 for reflection on the value of work overall and its place in their lives:
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21 “I just kept thinking if my cancer comes back and I’m working like this, I’m not going
22 to be happy ... I’ll die unhappy”. (Anna)
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27 At the same time, a sense of loss over the diminished importance of work was felt by others;
28 the cancer had forced a change and left them feeling uncertain and somewhat redundant:
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32 “It’s still in my mind that I’m not, I’m not there, that ‘there’ is not my future anymore.”
33 (Louise)
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38 As a result of their changing perceptions about work, all the women interviewed
39 contemplated changing their roles or careers or taking early retirement. There were some
40 who acted on this and who had already changed their jobs or profession:
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45 “I’ve got a part-time job now ... No stress, nothing, and that’s what I needed ... I want
46 to be happy in life without the worry and stress of something else ... I do know that if
47 I hadn’t had the cancer, I would still be working in my old job”. (Anna)
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52 Anna reflected on how having been diagnosed with cancer had disrupted and transformed
53 her approach to work. As a result of her diagnosis, any job that she takes on in the future will
54 have to match a new set of expectations and be stress and responsibility free. In contrast,
55 Fiona’s wish to reduce job-related stress was achieved through a plan to move sideways:
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3 “I still wanted to work in a similar area ... It is clear-cut and doable ... but I just felt
4 there could be less stress in a new job... I didn’t want the stress of starting to learn a
5 whole new job with a whole set of new skills ... a sideways move in the same kind of
6 area, I think is what I needed to do.” (Fiona)
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12 For these women, returning to their old job did not feel possible and they revised their
13 expectations of what sort of work they wanted to do. The main driver of such decisions
14 appeared to be reducing work-related stress. A career, as opposed to working, became less
15 important after being diagnosed with cancer. This is perhaps somewhat surprising among this
16 sample of professional women, many of whom had worked hard to obtain a high-level of
17 achievement in their job.
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25 “Life’s too short and you ... this isn’t really where you thought you would be career-
26 wise at this point in time. This isn’t quite how it was meant to be ... you need to take
27 stock and stop”. (Maggie)
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33 Maggie’s observations highlight how significant health-related events such as diagnosis and
34 treatment of cancer can derail not only one’s established goals but the overall *taken-for-*
35 *granted* trajectory of life. The seemingly trite comment that *life is too short* is anything but.
36 Rather it emphasises the need for clearly defined support for people navigating the complex
37 and longer term dynamic of work and cancer and who have been forced to face their
38 vulnerability and recognise their mortality.
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45 This first theme illustrates how having a diagnosis of cancer impacted on how the women
46 thought about work and careers and their meaning as result of being diagnosed with cancer.
47 Two contrasting lines of thought were obvious in their reports. The first was that having breast
48 cancer and dealing with it required them to change the importance that they placed on their
49 work and careers reducing the demands and stress that they placed on them so that they
50 could better cope with having cancer and with its treatment. The second was that continuing
51 to work would offer a distraction from cancer and help them maintain some sort of normality
52 especially leading up to treatment. Of course, these two lines of thought were not mutually
53 exclusive and could change across their cancer journey.
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5 **Theme 2: “You decide. It’s entirely up to you” Making decisions about work ability and**
6 **taking advice on work.**
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10 The changing meaning of work appeared intimately entwined with decisions about when and
11 how to work including the questions whether to work on following their diagnosis and, if not,
12 when to return to work. At diagnosis, most of the women decided to stay off work for the
13 duration of their treatment. They reported feeling that they would not be able to cope with
14 combining the responsibilities of work with cancer treatment. By staying off work, women
15 believed that they would allow themselves time and space to adjust to the diagnosis and focus
16 on their health.
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25 “... work was becoming far too much for me ... I was coming to work trying to be really
26 all things for all people ... eventually I was like “Actually I can’t do this” ... I wanted to
27 put myself and planning first. I wanted to ... make sure I had food in my freezer so if I
28 wasn’t able to cook I would have that... I must do all these things before my surgery
29 ...”. (Sophie)
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36 Three women chose to continue working up until the point of surgery. Work appeared to
37 provide them with a much needed distraction from ‘having cancer’ and gave them a sense of
38 normality during this challenging period.
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43 “... when I was diagnosed ... I had about a month before my appointment for surgery
44 so ... I just went into work I just worked right up to then because I just felt I needed
45 to keep busy and keep my mind off it”. (Abby)
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51 All of the women sought advice from healthcare providers regarding the optimal time to
52 return to work after radiotherapy or chemotherapy treatments were completed. A common
53 response from some primary and secondary providers appeared to be “return to work when
54 *you* feel ready”. Most professionals did make it clear that it was important for the women
55 not only to be *physically ready*, but also to *feel mentally strong enough* to achieve a
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3 successful work return. While this approach was intended to be supportive and give the
4 person ownership of the issue, it was found challenging by some.
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9 *“I said to the [consultant] “You know ... Well, should I be going back to work now or*
10 *should I stay off?” and they said, “It’s entirely up to you. Entirely up to you. You decide.*
11 *It’s entirely up to you”.* (Maggie)
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18 Interestingly, three women in the sample reported feeling pressured to return to work earlier
19 than was recommended by their employers.
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23 *“It was like you were being cajoled into coming back to work by occupational health.*
24 *It’s about time you gave it a shot because you’ve been off long enough”.* (Louise)
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29 *“I felt a lot of pressure was put on me in terms of making decisions about work. I felt a*
30 *bit backed into a corner. I thought maybe I should just leave my job and look for*
31 *something I can cope with...”.* (Rachel)
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36 In contrast, others were encouraged by their employers to return to work when they felt
37 ready to, which was informed by their managers’ understanding or personal experience of
38 cancer.
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43 *“I felt I wasn’t being pressured to return to work, that it was about me taking my time.*
44 *But I also thought that...because [my line manager] had had a diagnosis of breast*
45 *cancer that she did really understand...”* (Eva)
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51 The picture that this group of women painted regarding the advice that they were given about
52 decisions on work engagement and return to work from the different stakeholder groups
53 pointed up two important things. The first was that their HCPs often placed the key decisions
54 with them – “you will know when you are ready” while most of the women, at least initially,
55 looked to the former for that decision. It appeared that they did not always want to assume
56 responsibility highlighting that for these women, person-centred care meant working in
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3 partnership and being given advice when it was needed to help navigate their identity as
4 patient and as worker. The second thing was that the advice they received from their
5 employing organisation, including occupational health, was mixed. Where their senior
6 colleagues had some personal experience or understanding of cancer, they were felt to be
7 supportive and echo the advice given by the HCPs; otherwise they were felt to be less
8 supportive sometimes to the point of appearing to 'bully' the women back to work. This
9 provides two clear recommendations for HCPs and employing organisations.
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18 **Theme 3: "Maybe just a little note ... to say how are you?" The value of continued**
19 **engagement with employer from point of diagnosis and of workplace support.**
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23 The third theme that derived from the analysis concerned womens' experiences when
24 returning to work. These were grounded in the nature and strength of their engagement with
25 their employer and place of work from their diagnosis onwards. Those who had maintained
26 contact with their employer, in particular contact that was initiated and supported by the
27 employer, tended to report more positive experiences of returning to work than those who
28 had not received any such engagement or support. This was focused at the level of the
29 immediate employer or line manager and may be grounded in trust and the social processes
30 of the work environment.
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40 Across the sample, contact and offers of support from the workplace varied during the
41 women's leave of absence with some women receiving much support while others received
42 little or no contact and support. This was believed, in some cases, to be related to
43 organisational or other workplace policies. Nevertheless, most women had expected their
44 employer to initiate some form of contact during their leave of absence and viewed lack of
45 contact negatively.
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52 *"... [during] the interim period when I had my treatment, um, I didn't hear anything*
53 *from work, very disappointing, quite upset that ... not that you want people to be*
54 *thinking about you and things like that but I just thought really maybe just a little note*
55 *or a letter or a text or something to say how are you? ... I didn't receive that so that*
56 *was a real disappointment". (Helen)*
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5 Some women visited their workplace their leave of absence, which reduced some of their
6 fears about returning to work.
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10 *"... when I did go back to work ... it wasn't quite so scary as I had imagined because I*
11 *had been through the doors, I'd been up in the department, I'd seen a lot of the staff,*
12 *they were now completely aware of what was going on with me ... so I thought that*
13 *was a really good thing to have done..."*. (Emma)
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20 The majority of women returned to work on a period of phased return following advice from
21 occupational health. This was seen as helpful as it allowed them to readjust to work within
22 their new capabilities and perspective.
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26 *"... it was a bit daunting having not worked for nine months, you know, just being*
27 *dotting around the house and then to be back at work, it was quite, um, tiring to begin*
28 *with doing a full day ... it was useful having the phased return to sort of shorter days*
29 *until you work back up to speed..."* (Abby)
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36 Many women received adequate support and work accommodations from their employer
37 following their diagnosis and treatment. This included emotional and practical support, such
38 as a phased return to work, reduced hours, and the provision of sick pay:
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43 *"... if there's a supportive environment at work ... from the start ... that kind of attitude*
44 *... then it's much easier to return"*. (Rachel)
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49 However, this was not the case for all of the women we spoke to. A few women highlighted
50 that their employer was not as supportive as they had expected them to be. This was
51 attributed largely to their lack of understanding about the impact of cancer diagnosis and
52 treatment and of the women's cancer journey. This ultimately led to difficulties for women in
53 being able to effectively engage with work.
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3 *"... when you go back to work ... even though people are listening to what has*
4 *happened to you ... they're still expecting that 100% or they think they are ... that's*
5 *something that you have to be aware of. I certainly have been surprised at that..."*
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8 (Sam)
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12 Many women were anxious about returning to work after cancer due to the often extended
13 period of sick leave, and initially they found it difficult to adapt to work. These women
14 reported that they struggled to concentrate at work and perform cognitive tasks whilst
15 managing fatigue and pain as a consequence of cancer treatment or their emotional resilience
16 had declined following their cancer experience.
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23 *"... it was a really difficult time [at work] ... and I think because I'd been there so long*
24 *everyone looked to me to keep things going it was useful to take that time out and*
25 *just realise that there's other people as capable as me so they can all just share the*
26 *load..."*. (Abby)
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32 The contrasting experiences of the woman in this group demonstrate the complex interplay
33 between the women's adjustment to their cancer diagnosis, the changing meaning of
34 work, their readiness and ability to return to work and the behaviour of their employer
35 (grounded in their own understanding of cancer). It is also clear that there is an important
36 relational context with work colleagues in this meaning making. This further highlights the
37 importance of clear communication and understanding between all the key stakeholders in
38 the return to work process.
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47 **Discussion**

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49 This study provides unique insight into the meaning of work following a cancer diagnosis for
50 professional working women living with breast cancer in Scotland. In particular, it allows for
51 a deeper understanding of the complex interplay between living with cancer, treatment and
52 related work decisions and how advice and support shaped their work engagement. These
53 findings are resonant with the current European and North American literature (e.g. (32,33))
54 and build our knowledge in this area.
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3 There was no prioritisation of work over health and treatment for these women. As might be
4 expected from the existing literature, work was clearly important for them before their
5 diagnosis of breast cancer (34,35) and this appears to be tied in with both the meaning of
6 work for them and to their sense of identity. Cancer threatened their self-identity and often
7 led to a felt loss of control and, subsequently, to a search for the meaning of work. While it
8 is known that cancer can prompt a shift in priorities (16,33), the novel finding here is the
9 nuanced understanding of why and how. A key theme for the women in this study was how
10 the experienced loss of control led to a shift in identity and altered priorities. This was
11 grounded in the need to protect their self-identity, and to recover from feeling lost and
12 diminished by their cancer. While work remained important to the majority of women in this
13 study, for psychological as well as financial reasons, many desired a better work-life balance
14 and way of working that would restore a sense of self and of control and would allow a focus
15 on new priorities. A change in meaning has been reported in previous studies focused on
16 change in work priorities and reduction / changes in working practice (11,24,36). For the
17 women in the current study, the change in meaning marked a shift from pursuit of career and
18 work as everything to self as important and work-life balance.

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34 The second novel finding is the issue of work ability being handed back to the women to make
35 a judgement and their feelings of not being prepared. Work ability has been much debated
36 and studied within the broader cancer literature (20,22,37,38) but there is little in terms of
37 how this judgement is made and whom this decision involves. The role of HCPs has also been
38 highlighted to a lesser extent (e.g. (8,39)) but with regards to meeting information needs and
39 appropriate discussion of work rather than around judgements of work ability. Similarly,
40 occupational health and occupational physicians have been highlighted as key stakeholder
41 groups within the delivery of return to work interventions (e.g. (40)) and yet this study shows
42 the negative impact of getting these decisions wrong and women feeling additional pressure
43 from occupational health providers. This highlights that the importance of facilitating
44 agreement between the individual, the health care provider and the organisation about
45 readiness and ability to return to work (9,22) and also of achieving non-tokenistic person-
46 centred care.

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3 The third novel finding is the complex interplay between the individual level adaptation and
4 the behaviour of the employer. The literature focuses on the role of large organisations and
5 organisational behaviour (41) or the role of occupational health in making reasonable and
6 practicable accommodations as a minimum requirement (42). This is directed in the UK by the
7 Equalities Act (43). A highlighted gap in the literature is around what employers within
8 organisations should be doing beyond their legal duty of care and how to facilitate
9 implementation of recommendations (33,44–46). Current understanding within the cancer
10 literature is framed within the context of North American and Northern European
11 employment practices and healthcare systems (47–50). This study extended the debate
12 around employer behaviour and demonstrates the importance of the individual line
13 manager’s behaviour in determining the women’s experience of return to work. Contact with
14 the individual line manager, rather than the organisation, while undergoing treatment was
15 felt to be a positive driver in remaining engaged with work. This allowed women to return to
16 the workplace while managing the cognitive, emotional and existential aspects of living with
17 and beyond breast cancer. This social contact, therefore, is a crucial element in the delivery
18 of accommodations at work that support the person’s needs. Hakanen & Lindbohm (51) also
19 highlight the importance of social resources at work to support work engagement following
20 a diagnosis of cancer. Our findings make clear the importance of realistic and supportive
21 advice given in relation to work and help provided in shaping work-related decisions across
22 the women’s cancer journey. Clear consensus and guidance is a recommendation echoed
23 within the existing literature (11,20,25,34). It is also evident from our findings that there are
24 multiple aspects of the meaning of work, which include the psychosocial work environment,
25 that are important following a diagnosis of cancer. This requires further study.
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47 In turn, the findings do imply a need to provide line-managers, occupational health and HCPs
48 with appropriate and up-to-date evidence-based knowledge and training to ensure that they
49 can provide information and advice. Despite being highlighted in previous studies, there is
50 still an acknowledged need for clear systems in place for the exchange of information
51 between these groups and other stakeholders (2,11,34).
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58 This study makes a strong contribution to knowledge. It is, however, important to recognise
59 the limitations of this work. As was the intention, this is grounded within a UK context. Given
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3 the professional background of the women, access to additional financial resources may have
4 influenced the decisions that they subsequently made about work. There is a need to also
5 explore the lived experiences of women working in non-professional and insecure
6 occupations, to understand the unique challenges faced by this population. The interviews
7 were conducted either face-to-face or by telephone raising the question of whether the
8 method used effected the data collected. The data from the 15 participants were scrutinised
9 to determine whether or not there were obvious and substantive differences by method.
10 None were detected.
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20 **Conclusion**

21 The findings from this study demonstrate the complex interplay between living with cancer,
22 treatment decisions and work. The goal of research in this area is to develop
23 recommendations for health care and work-based practice to support working women with
24 breast cancer in relation to work engagement, in the way in which they desire. This study
25 highlights two key areas for inclusion in practice: 1) support from HCPs in managing the
26 diagnosis of cancer and threats to self-identity and judgements of functional ability and work
27 ability and 2) the role of others in managing cancer, treatment and work, in particular line
28 managers within the organisation.
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38 **Word count 4,995 excluding abstract, table and refs**
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Table 1: Demographic characteristics

	Mean (SD) or n (%)
Age (years)	51.7 (5.3) Range 39-59
Marital Status	
Single	3 (20%)
Married or Civil Partnership	9 (60%)
Separated or Divorced	3 (20%)
Diagnosis	
Ductal Carcinoma in Situ (DCIS)	2 (13.3%)
Grade 1	2 (13.3%)
Grade 2	4 (26.7%)
Grade 3	6 (40.0%)
Missing	1 (6.7%)
Cancer treatment	
Lumpectomy	11 (73.3%)
Mastectomy	5 (33.3%)
Chemotherapy	8 (53.3%)
Radiotherapy	12 (80%)
Hormone Therapy	12 (80%)
Biological Therapy	1 (6.7%)
Educational Level	
Diploma/HND/HNC	7 (46.7%)
Bachelor's Degree	6 (40%)
Master's Degree	1 (6.7%)
Professional Degree	1 (6.7%)
Occupation*	
Healthcare	4 (26.7%)
Education	4 (26.7%)
Business and related research professionals	3 (20%)
Marketing and sales	1 (6.7%)
Protective services	1 (6.7%)
Public services	1 (6.7%)
Social services	1 (6.7%)
Work status at diagnosis	
Working full-time	6 (40.0%)
Working part-time	5 (33.3%)
Self-employed	1 (6.7%)
Work continuation during treatment	
Yes	2 (13.3%)
No	13 (86.7%)
Current work status	
Working full-time	6 (40%)
Working part-time	4 (26.7%)
Self-employed	1 (6.7%)

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Not currently working/on sick leave	3 (20%)
Retired	1 (6.7%)

For Peer Review

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