‘Getting back to normal’ or ‘a new type of normal’? A qualitative study of patients’ responses to the existential threat of cancer

Paul Baker¹, Helen Beesley², Ian Fletcher³, Jan Ablett², Christopher Holcombe² and Peter Salmon⁴

¹ Clinical and Health Psychology Section, School of Psychological Sciences, University of Manchester, Manchester, UK
² Royal Liverpool and Broadgreen University Hospital NHS Trust, Liverpool, UK
³ Division of Health Research, University of Lancaster, Lancaster, UK
⁴ Division of Clinical Psychology, University of Liverpool, Liverpool, UK
ABSTRACT

Existential concerns about cancer have been studied extensively in palliative care but less so in curative settings. The present report aims to describe ways in which patients viewed the continuity or discontinuity of their identity in the face of the mortal threat of cancer. Twenty-eight patients with breast, prostate or lung cancer attending pre-treatment, treatment or follow-up appointments were interviewed about their emotional experiences following diagnosis. Qualitative analysis followed an inductive, constant comparative approach. Patients spoke of ‘getting back to normal’, but presented two distinct accounts of ‘normality’. Some, particularly those only recently diagnosed, maintained continuity to past identity by upholding previous routines, emphasising resilience and minimising the impact of cancer. Others talked of a new ‘normality’ discontinuous with their past. Most accounts, however, evidenced elements of continuity and discontinuity, often in ostensibly contradictory ways. We suggest that holding contradictory perspectives simultaneously characterises an intermediate stage of adjustment for some patients: between reliance on continuity with the past in the aftermath of diagnosis and, later, a sense of being a new person, changed by cancer. Practitioners should appreciate that patients’ wishes for ‘normality’ can signify very different responses to cancer, and that holding such contradictory orientations is functional, not aberrant.

Keywords: cancer; existence; emotional distress; identity; disavowal
INTRODUCTION

Although advances in treatment have greatly improved survival, cancer is still often a fatal disease accounting for 8.2 million deaths annually worldwide in 2012 (Ferlay et al., 2013). Moreover, even where cancer is curable or, effectively, ‘chronic’, there remain substantial misconceptions and negative conceptualisations in the illness representations of cancer in the general population (Anagnostopoulos and Spanea, 2005, Castillo et al., 2011, Holland, 1998, Ramers-Verhoeven et al., 2013). For many, the disease is synonymous with an untimely and undignified death (Geraghty et al., 2002) and the prospect of ‘sudden amputation of the future’ (Frank-Stromberg et al., 1984). A diagnosis of cancer, therefore, regardless of prognosis, confronts an individual with threats to their mortality and invalidation of previously held assumptions about the future, which some authors have described as ‘existential threat’ (Blinderman and Cherny, 2005, Moadel et al., 1999, Moorey and Greer, 2012, Salander, 2000, Taylor et al., 1999, Westman et al., 2006). Given that identity and existence are closely linked, in that to exist means to have an identity (Olson, 2007), existential threat associated with cancer can be manifest as a sense that one’s identity is also threatened (Leveälahti et al., 2007, Little et al., 2002).

Research has investigated processes of psychological adjustment that are triggered by confronting the threat of mortality associated with cancer, particularly posttraumatic growth (Connerty and Knott, 2013, Cordova et al., 2007, Horgan et al., 2011, Stanton et al., 2006), whereby positive psychological change can emerge both during and following a traumatic experience. Some writers have applied Bury’s concept of ‘biographical disruption’ (Bury, 1982, Bury, 1991) to understand how
encountering cancer disrupts patients’ assumptions about themselves and leads them to evaluate life differently and come to accept mortality (Cayless et al., 2010, Coreil et al., 2012, Denford et al., 2011, Hubbard et al., 2010, Leveälähti et al., 2007, Reeve et al., 2010). Psychological interventions in palliative settings have explored ways of supporting patients in this process of readjustment (Breitbart, 2002, Breitbart et al., 2004, LeMay and Wilson, 2008).

In curative care, however, patients with cancer commonly report an expectation or desire to ‘get back to normal’ following treatment (Costanzo et al., 2007, Denford et al., 2011, Little and Sayers, 2004). Moreover, psychological intervention research in curative settings has concentrated on the restoration of mood and function (Costanzo et al., 2007), and helping patients towards an ‘ordinary life’ through resisting the effects of cancer (Moorey and Greer, 2012, Naaman et al., 2009b). Nevertheless, several studies have suggested that concerns about identity and existence are important for patients who are receiving, or have completed, curative treatment (Bowie et al., 2005, Brady et al., 1999, Lagerdahl et al., 2014, Moadel et al., 1999, Salander, 2000, Swinton et al., 2011, Westman et al., 2006) and that practitioners do not routinely address these concerns (Wexler and Corn, 2012). However, there is therefore potentially a tension for practitioners between addressing patients’ expressed wishes to ‘get back to normal’ and helping them create a new identity. Much more research is needed to understand how patients understand and manage existential concerns and how practitioners can help them (Henoch and Danielson, 2009).
The present report arose out of a study of the psychological needs of patients after diagnosis of cancers of varying prognoses (Baker et al., 2013). We noticed that many patients referred to ‘getting back to normal’, but what they meant by ‘normal’ varied between accounts. Patients held different, and even conflicting, views about the continuity or discontinuity of their present identity with life before diagnosis. Therefore this report describes the main elements of these views and considers implications for our understanding of how patients respond to the existential threat of cancer and for their psychological needs.
METHOD

Setting

Patients were recruited from clinics at three hospitals in North West England. The services did not provide routine psychological care following diagnosis, although patients had access to clinical nurse specialists who provided tumour-specific emotional support, including reassurance, information and simple advice on managing emotional difficulties. Patients also received an information leaflet about emotional reactions to cancer, described previously (Baker et al., 2013).

Relationship to the larger study

The patients reported here are a subset (see below) of those in a larger qualitative study of patients with breast, prostate or lung cancer (Baker et al., 2013). That study described patients’ psychological needs and how they differed according to the time since diagnosis. Consistent with the ‘progressive focusing’ of qualitative research (Murphy et al, 1998) we extended our aims to include those of the present report, which describes an additional line of analysis conducted on a subsample of patients in parallel with the main analysis of psychological needs in the complete sample.

Sampling and participants
Following ethical approval (reference: 10/H1002/62), a purposive sample was recruited over seven months, encompassing the range of ages, treatment experiences and psychosocial distress routinely seen in the study clinics. Patients with breast, lung or prostate cancer were recruited at different stages of treatment from diagnosis to 18 months later. Patients were excluded if they were under 18 years old, or were considered by their care team to be unable to provide informed consent due to cognitive impairment, physical condition or intense distress.

Patients were recruited from routine assessment, treatment and follow-up clinics. Initial study information was provided by a nurse or clinician; those interested in participation were then introduced to PB or a second researcher who obtained written consent. Participants were interviewed in their own homes by one of the two researchers four weeks later.

From a pool of approximately 80 eligible patients, 61 were approached and 53 consented. Nine subsequently withdrew before the interview and two could not be contacted. Of the 42 patients interviewed for the wider study, 28 alluded to the continuity or discontinuity of their existence or identity and formed the sample for this report (see table 1).

**TABLE1.**

*Interviews and data analysis*
Semi-structured interviews adhered to a topic guide, where patients were encouraged to talk about: how they had coped with the psychological challenges since diagnosis; their attitudes to the future; their emotional state and emotional needs and how these had evolved since diagnosis; and their views of the information leaflet about emotional reactions to cancer. The guide was refined progressively throughout analysis, which ran in parallel with the interviews. In particular, because patients consistently talked of the importance of ‘getting back to normal’, they were prompted to discuss what ‘normal’ meant. Interviews were digitally audio-recorded and transcribed verbatim. The median duration of the interviews was 47 minutes (range: 32-89 minutes).

Qualitative analysis followed an inductive, constant comparative approach drawing from a grounded theory framework (Murphy et al., 1998). Analysis started descriptively, but became more interpretative as we developed analytic categories to describe the content, meaning and function of what was said in the context of the local dialogue and the interview as a whole, and in the context of other interviews. Analysis was led by PB, HB and PS, who read and re-read all transcripts, and findings were further tested and refined through discussion amongst all authors who read extracts of transcripts. Interviews conducted earlier were revisited as we developed the analysis following later interviews. Preliminary findings were presented at meetings of patient support groups and each tumour group’s multidisciplinary team.

Although qualitative research cannot yield generalisable quantitative information, counting instances of qualitative findings (sometimes called ‘quantitising’
(Dixon-Woods et al., 2004) can help to test the completeness of the analysis. That is, it addresses internal validity rather than, as in quantitative research, external validity. We therefore counted the patients whose accounts displayed the main categories of analysis.

Excerpts from transcript are provided below to illustrate the main features of the analysis, identifying patients by a code indicating their tumour group (B, L or P, for breast, prostate and lung, respectively) and participant number. Ellipses indicate omitted text and square brackets denote explanatory comments.
RESULTS

In examining the data to understand patients’ psychological needs (see above), we noticed from the start that many patients emphasised the need to live a ‘normal’ life and, as explained above, we included this as a focus for interview. Analysis of what patients meant by ‘normal’ exposed two distinct meanings, each signifying a different view of the continuity of their existence. Some accounts were of normality as continuity with the past, emphasising minimal disruption by cancer. Other accounts projected normality into a future discontinuous with the past in that it was changed or constrained by cancer. Most patients’ talk indicated elements of each way of viewing normality. These views are first described separately below and then their co-existence is examined. We found no differences between patients with different types of cancer. Differences between patients at different stages in the cancer journey are highlighted below.

‘Normality’ as continuity with the past

Many patients talked of the importance of normality in the sense of maintaining ‘normal’ routines and priorities, “carrying on regardless”[L2], and of wanting to “get back to my old self”[P10]. They described cancer as a “minor inconvenience”[P1] or “blip”[B7] that would only transiently distract them from living ‘normal’ lives. Analysis identified several ways in which patients asserted continuity with pre-cancer life.
Asserting biographical continuity

Patients provided biographical narratives which emphasised continuity with who they were before their diagnosis, and which implied that they would remain the same person after their cancer had been treated. These narratives often emerged when patients drew on previous experiences to explain their reactions to cancer. For example, many attributed their resilience to enduring personality traits, such as having “always been a positive thinker”[P13]. Others described how previous physical or emotional adversity equipped them to manage the experience of cancer; for example, L7 talked about how previous army experience gave him a “frame of mind” and “a strong personality [to] take everything in your stride”. Patients also attributed resilience to their upbringing and personal beliefs. L4 talked about how her “very strict” upbringing had “taught [me] to control my emotions”. B6 ascribed her confidence in her ability to cope with cancer to her long-standing belief that “God won’t give you anything more to cope with than you can”.

Many patients therefore emphasised the negligible impact that cancer had on their lives, minimising any consequence of the illness, such as feelings of emotional or physical weakness, as “natural reactions”[P1] or “silly things”[B6].

“You have negative thoughts at times, but then you think ‘Oh, don’t be ridiculous! Everything you’ve been through so far has been positive.’”[B7]
They described minimising the impact of their illness in discussion with family and friends. Although some attributed this to a need to protect those close to them ("If I go downhill, the kids will too"[B10]), others minimised in the effort to return to previous routines. For example B5, recovering from breast surgery, described her frustration at her family’s attempts to limit her activities.

“They won’t let me do any shopping, won’t let me lift heavy bags... I said to them ‘Oh, good God, I’ve had my op. I’m alright...I think they’re being over-protective’"[B5]

In describing continuity between their past and present, patients therefore portrayed cancer as alien and intrusive.

“I’m still fit. I’m still me. It’s just a bug inside me” [L7]

*Suppressing discontinuity with the past*

Despite framing cancer as a fleeting departure from normality, pervasive language of effort and agency evidenced the difficulty of asserting continuity to the past. Although some patients described “plodding on”[P5], most described the importance of "keeping positive", "fighting" or "beating" the disease by resisting its disruptive effects on their lives and mood, particularly in describing self-talk.
“You try and stay positive, you say to yourself ‘You can get through this, you can fight it’... ‘You are not taking me’” [L5]

Many patients described strenuously avoiding ‘reminders’ of their illness and vulnerability. For example, P10 described how “making a conscious effort to get up off your backside and do things” prevented him “dwelling” on his illness. That is, patients did not describe simply becoming unaware of reminders; rather, they chose to disregard them, and doing so was effortful. L2, for instance, described trying to “forget about [cancer] all I can.” Confronted by his continuing weight loss, he responded by “not weighing myself as much ... because it gives me peace of mind”. When prompted by the interviewer about how he would manage distress should he continue to deteriorate, he insisted:

“I’d rather we didn’t talk about that...It’s put right to the back of the queue at the moment”[L2]

The drive to avoid such reminders extended to rejecting potential opportunities for support. L4, for example, described how “It doesn’t bother me when [nurses] give me books, but when I read them it does...I say ‘Oh no, I don’t want that’.” P10 described a similar reaction to attending support groups.

“I went with positive attitudes...but when I sat down and had a coffee with them...I felt as though there was more bad things being heaped on me...One guy is having his bowels cauterised regularly and I thought ‘Oh my God...I don’t want to be told about this’”[P10]
‘Normality’ as a future discontinuous with the past

By contrast, many patients embraced discontinuity with the past in describing themselves as changed by the cancer. Rather than experiencing cancer as an external threat to identity, patients spoke of a life in which illness was a defining component of identity. Where these accounts emphasised returning to ‘normal’, normality incorporated, or was changed by, cancer and its consequences.

“I’ve been trying to keep everything as normal as possible... that can be hard as some things aren’t the same after...it’s a new type of normality”[B14]

Associated with this sense that ‘normal’ meant something new rather than familiar, we identified several ways that patients projected a sense of normality into a changed or uncertain future.

Becoming someone ‘new’, with new values

Patients described a permanent change to their sense of identity, which incorporated their experience of cancer. Many described this change as a positive consequence – they had become more resilient and reflective having lived through cancer. P10, for example, described how he felt that “you become more blasé as you go through life. I think if something traumatic happens…you reflect on things, you
take stock”. He recounted, for instance, new-found enthusiasm for his family. Similarly, B11 explained how her diagnosis had changed her priorities, such as “[not caring] about housework anymore...I used to stress about it but now I don’t. I hope it stays that way”.

As with accounts emphasising continuity with the past, those projecting their identity into a future discontinuous with the past included reflections on previous experiences and personal beliefs. However, rather than portraying these as sources of resilience to being changed by adversity, patients emphasised their flexibility and capacity to grow. L1, for instance, described how following previous life stress he felt he “could take on anything”.

Normalising mortality

A few patients’ accounts viewed death, itself, as ‘normal’, or as a kind of continuity, rather than an abrupt and unwarranted discontinuity. P13, for example, normalised his experience of cancer and the threat of extinction by likening himself to “an old motor car… because your body starts wearing out”. For him, cancer and the prospect of death was an anticipated stage in his life. B10, similarly, ascribed her equable reaction to diagnosis to age, explaining that the impact had been tempered by her sense of personal accomplishment.

“I’m 70…I’ve lived to see all my kids grow up and if the push comes to shove, well I have lived…It’s not like I’m a 40 year old who’s got young kids”[B10]
L6 described how pre-existing illnesses had already confronted him with the prospect of his death.

“So by the time cancer came round, there’s not a lot of emotion left. ‘Cos the thrombosis can kill me, the heart [disease] can kill me…the actual lung cancer hasn’t affected me at all”[L6]

Coexistence of different orientations to ‘normality’

Of the 28 patients included in this study, only 11 described exclusively a single orientation. Seven of these described continuity to the past, all of whom were relatively early in their cancer trajectory and had not yet begun treatment. Four patients’ accounts indicated complete acceptance of discontinuity, and all these had reached the stage of being engaged in or having completed treatment. This suggests that emphasising continuity with the past might, in some patients, give way to accepting discontinuity. However, most accounts (17 out of the 28 patients) contained more than one orientation, often in ostensibly contradictory ways. For example, L7 (Box 1) described, in different parts of the interview, being unaffected by cancer and planning for his death because of the cancer. Similarly, L11 (Box 2) emphasised continuity with her previous life and rejected the significance of cancer whereas, elsewhere in her interview, she described her vulnerability, shortened lifespan and ways in which cancer had changed her. Of these 17 patients, seven had
not yet begun adjuvant treatment and ten were approaching, or had recently reached, the end of treatment.

BOX1 & BOX 2 HERE
DISCUSSION

Overview of findings

Faced with the existential threat posed by cancer, patients gave contrasting views of the continuity of their identity. Some, particularly those early in the cancer trajectory, asserted their continuity to the past. They described cancer as a ‘blip’ in their lives, curtailed their thoughts of the future and emphasised living day-to-day. Others, particularly those who had begun or completed treatment, envisaged a new future discontinuous from their past, in which cancer became a defining feature of the self. However, most patients held different – sometimes contradictory – views simultaneously, regardless of their stage in the cancer journey.

Relationship to previous literature

Although existential concerns have been widely acknowledged in palliative care, our findings add to the evidence that existential issues including questioning one’s sense of identity, finding meaning in the cancer experience, and confronting mortality, are important in the psychological adjustment even of patients receiving curative treatment.

Some writers have used the concept of ‘posttraumatic growth’ to understand psychological changes that are associated with cancer for some patients (Connerty and Knott, 2013, Cordova et al., 2007, Horgan et al., 2011, Stanton et al., 2006), Our
findings do not easily accord with the implication of an improved psychological state. Even patients who described a changed sense of identity could also describe being unhappy or distressed. Other writers have used the concepts of ‘biographical disruption’ and ‘biographical flow’ to understand how cancer affects patients’ assumptions about their existence and their sense of identity (Cayless et al., 2010, Coreil et al., 2012, Denford et al., 2011, Leveälahti et al., 2007, Reeve et al., 2010). Our findings show some similarities with these concepts: some patients viewed cancer as a disruption to be negotiated and some spoke of integrating illness into their sense of self. However, our findings go beyond these concepts in two respects. Firstly, most patients did not appear to have a pervasive cognitive structure around rejecting cancer or assimilating it into a new identity; rather, as has been suggested recently (Hubbard and Forbat, 2012), conflicting responses to cancer could coexist despite inherent contradiction. Secondly, our findings evidence the effort required to maintain continuity with past identities. This indicates the psychological importance of a sense of continuity with the past for those patients who asserted it. Patients were not simply ‘in denial’, but engaged actively in the construction of a personal story that mitigated the devastation of cancer.

These findings provide empirical support for Salander’s application of Winnicott’s (1977) concept of the ‘intermediate area’ to cancer (Salander, 2007, Salander, 2012), whereby patients cope with the strain of cancer by constructing an ‘intermediate area’ between external reality and their internal world. Faced with the harsh reality of cancer, patients can inhabit this area, ‘playing’ with different versions of reality – even to the extent of alluding to a life expectancy of 20 years and 2 years in the same interview (Box 2). Our findings support Salander’s (2012) suggestion
that patients are not ignorant of the severity of their condition but, by using the ‘intermediate area’, are able to keep different views of the future in play in order to maintain hope in the face of this threat. As patients in the present study whose accounts solely emphasised continuity to a past life were early in the cancer trajectory, and those who talked solely of embracing a new future were much later, it is possible that the ‘intermediate area’ is particularly important as an intermediate stage of adjustment. That is, through entertaining contradictory views, patients can transition from a life without cancer to a new ‘normality’ incorporating the disease.

**Limitations of the study**

As a qualitative study, these findings cannot automatically be generalised. However, we studied patients with varying prognoses and cancer types, and our findings were consistent across the different patient groups, suggesting that they may have some broad applicability. Our process of ‘quantitising’ our findings supports internal validity but cannot support external validity. That is, whether these counts would be similar in a different sample, or with different researchers, is unclear without further research. Lastly, the study was not directly designed to explore patients’ reactions to threats to existence and identity, and some patients’ accounts provided insufficient relevant data for inclusion in this analysis. Nevertheless, that most patients who were interviewed about their psychological needs in relation to cancer spontaneously talked in ways that indicated constructions of the continuity or discontinuity of their identity suggests that the present report concerns a subject important to patients’ psychological adjustment.
Research and clinical implications

Our findings suggest the need for research in two linked areas. The first is to test our suggestion that holding contradictory constructions of one’s continuity is, for many patients, an intermediate stage in adjustment. Demonstrating generalisability of this finding would indicate that those providing psychological support need to be oriented to different patient goals at different stages in the cancer trajectory. Secondly, considering the relatively modest efficacy of conventional cognitive interventions in reducing cancer-related distress (Naaman et al., 2009a), there may be potential for practitioners to provide more effective psychological support by facilitating creation of ‘intermediate areas’ within which patients can be helped to explore different constructions of the continuity of their identity.

The present findings already have potential implications for supportive and psychological care for patients with cancer. First, they show that patients can have disparate, even contradictory, psychological goals during and following treatment for cancer. In clinical practice, this means that practitioners must not be misled by patients’ culturally normative language. In particular, many patients in this study referred to wanting a ‘normal’ life, and previous research has also emphasised patients’ desire for a ‘return to normality’ following treatment (Denford et al., 2011). Our findings show, however, that normality can mean different things. It can signify adhering to routines and assumptions from life before cancer; but it can also mean becoming comfortable with a new sense of self, shaped by cancer (Sandsund et al.,
Because most patients in the present study drew on both accounts, statements of a desire to ‘get back to normal’ need careful interpretation rather than to be taken literally.

Practitioners also need to be tolerant of the ambiguity that patients bring when they occupy seemingly contradictory states. Practitioners’ role (whether in supportive or specialist psychological care) is often regarded as helping patients to ‘adjust’ to cancer, for example as ‘catalysts’ of the processes underlying adjustment or as ‘midwives’ facilitating developmental transition (Brennan, 2001, Moorey and Greer, 2012). The present analysis suggests the need for a different view. Salander (2012) described practitioners’ role in creating the ‘intermediate area’ within which patients can ‘play’ with their constructions of reality. On this reasoning, the practitioner has to be able to adopt the role of a ‘play therapist’, allowing the patient to ‘try out’ different views of their world from which they can derive meaning and comfort in the face of their experience of an adverse reality. In adopting this role, practitioners should avoid assuming that patients who emphasise continuity with their past life, to the extent of minimising the implications of cancer, are ‘in denial’. In the present study, the concurrence of conflicting views in patients’ talk indicates that asserting continuity with a life unchanged by cancer can coexist with awareness of reality. Practitioners therefore need to respect patients’ ‘disavowal’; seeking to counter this may contradict patients’ natural ways of coping with the existential threat of cancer.
REFERENCES


BAKER, P., BEESLEY, H., DINWOODIE, R., FLETCHER, I., ABLETT, J., HOLCOMBE, C. & SALMON, P. 2013. 'You're putting thoughts into my head': a qualitative study of the readiness of patients with breast, lung or prostate cancer to address emotional needs through the first 18 months after diagnosis. *Psycho-Oncology*, 22, 1402-10.


ACKNOWLEDGEMENTS

The study was funded by Liverpool PCT through the Liverpool Health Inequalities Research Institute. The authors thank: Philip Cornford, Susan O'Reilly, Nicky Thorp, Martin Walshaw and the oncology teams at Royal Liverpool University Hospital and Liverpool Heart and Chest Hospital for their enthusiastic participation in patient recruitment; Rose Moran and Gill Hamblin for their participation in the design of the study and securing funding; Rob Dinwoodie for assistance with conducting interviews; and Margaret Shields for advice on the proposal and this paper. We are grateful to the patients who gave time to be interviewed for this study.
Table 1. Characteristics of the study sample

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Breast (n = 9)</th>
<th>Prostate (n = 10)</th>
<th>Lung (n = 9)</th>
<th>Total (n = 28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>59.1 (6.6)</td>
<td>63.7 (10.0)</td>
<td>66.2 (11.5)</td>
<td>63.4 (9.8)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>0</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>10</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British/Irish</td>
<td>9</td>
<td>10</td>
<td>9</td>
<td>28</td>
</tr>
<tr>
<td>Black/Minority Ethnic Groups</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Stage of cancer at recruitment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Stage II</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Stage III</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Stage IV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Time post-diagnosis at recruitment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;3 months</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>3 - 6 months</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>6 - 9 months</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>9 - 12 months</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>12 - 15 months</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>15 - 18 months</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Treatments received before recruitment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>9</td>
<td>4</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>7</td>
<td>3</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>5</td>
<td>6</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>Hormones</td>
<td>6</td>
<td>7</td>
<td>n/a</td>
<td>13</td>
</tr>
<tr>
<td>Active surveillance only</td>
<td>n/a</td>
<td>1</td>
<td>n/a</td>
<td>1</td>
</tr>
<tr>
<td>Treatment plan undecided at time of interview</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

1 Some patients received more than one form of treatment
L7 had been diagnosed with small cell lung cancer four weeks before interview and, at the time of interview, was waiting to begin chemotherapy. He had pressed for chemotherapy as a way to fight the challenge of cancer in the face of his oncologist’s recommendation against it.

[Oncologist] said to me ‘We normally send people home of your age’. I’m 75…So I said ‘Oh no…I’m fit, I still go to the gym three times a week. You can’t write me off’… And he’s a fat little guy…he’s gonna die before me looking at the state of him.

When asked about the changes to his life since diagnosis, he consistently minimised his illness, at one point comparing cancer to toothache,

I’m still fit…Absolutely nothing’s changed… It’s just a matter of fact. Like I’ve got toothache, and I’ve got cancer. There’s nothing you can do about it, so I won’t worry about it…I never say ‘Oh, I’ve got cancer’, it never enters my mind…I’ve put it on the back burner, to be perfectly honest.

Similarly, when talking about the implications of cancer for his life-expectancy, he insisted that.

It’s only when you’re laying in the bed and the priest has been…you know you’re going [dying] then. But not while I’m still walking the streets. I’m still fit…I’m stronger than this. I honestly feel I’m stronger. I do not want to die, not for a long while yet… I mean I’m not being blasé. I feel there’s no need worrying about it.

When talking further about his attitude to anticipating his death, he described actively avoiding preparing for it: ‘if I get my house in order, I’ve given in’. However, later in the interview, he talked in some detail about how he had started to anticipate death and to prepare for it.

I’ve got a lot to do in the house. I’ve got files, being ex-Army means everything’s in files. I’ve got to start burning them. I’ve got things to sell and get rid of…I’ve had these weeks to think about it. I haven’t put my house in order yet but I know what I’ve got to do.
Box 2. Emphasising continuity with the past while describing a changed and shortened future

L11 had been diagnosed two months previously with non-small cell lung cancer. At the time of the interview she was recovering from her first dose of chemotherapy.

At the start of the interview, she consistently emphasised that treatment was not disruptive and that ‘I just don’t feel sick at all’. She acknowledged that, although she appears ‘sick because…I’ve lost my hair’, she feels ‘brilliant’. Although she had experienced some ‘down days’ since diagnosis, she described self-talk that minimised the influence of cancer on her life:

I’ve just got to think positive… I keep saying ‘You can’t be taking me yet because I’m only 52, 53, too young to go yet’. Little things go through my head like, but then I just say, ‘no, you’re not taking me, think positive’. I’ve got at least another 20 years yet.

She described the effort of holding on to ‘normal’ routines so as to stay ‘positive’.

I just liked lying in my bed before I got told [I had cancer]…and now I don’t stay in bed now…Because I’m sick and I know, and if I lie in bed I start thinking all kinds in my head and that.

However, later in the interview, she also described ways in which she had embraced being changed by cancer. She described how she had changed as a person, particularly in becoming able to disclose emotion.

[Before diagnosis] I didn’t cry in front of my kids but now I do…I cry in front of them now, it’s more helpful because before I was bottling it in, in front of them because they are upset…Now I just burst out crying… it does help me.

Similarly, in contrast to her assertion, above, that she had ‘at least another 20 years’, she explicitly talked of accepting her shortened life expectancy.

I’ve just got to try and get on with it. I’m happy with life. Well I’m not happy, like, but I’ve got to get on with, it haven’t I? Because it’s a cancer what they can’t cure anyway, isn’t it? Just hoping I get at least a couple of years out of it.