

What are the holistic experiences of adults living long-term with the consequences of cancer and its treatment? A qualitative evidence synthesis.

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## INTRODUCTION

Improvements in the detection and treatment of cancer, a rise in cancer prevalence and an ageing population in the UK means that an increasing number of people are living with and beyond cancer (Linden et al., 2016). Whilst some cancers do continue to have a poor prognosis (McConnell et al., 2017) and survival rates vary between countries, survival rates overall across Europe are increasing (De Angelis et al., 2014). Cancer survival rates in the UK have doubled in the last 40 years (Cancer Research UK, 2020) and it is predicted that by 2040 there will be more than five million people living with cancer in the UK (Maddams et al., 2012). A significant number of those surviving cancer, defined by Maher et al. (2018, p. 76) “living longer term with chronic cancer or post-curative treatment”, will experience ongoing consequences after treatment. A range of consequences can affect holistic experiences, encompassing physical and psychological health and social wellbeing (Macmillan Cancer Support, 2015). These ongoing symptoms can lead to a reduction in health-related quality of life (Götze et al., 2018). As many as one in four cancer survivors will experience moderate or severe physical or psychological issues following cancer treatment (Maher et al., 2018), this rises to 30% of people for certain cancer types (Armes et al., 2009).

The NHS Long Term Plan in England (2019) prioritises improving cancer survival rates but Macmillan Cancer Support (2015) stress that surviving cancer is not the same as living well after cancer. Attention must be paid to quality of life and the ongoing nature of the consequences of cancer and its treatment, beyond the acute care phase. Macmillan Cancer Support (2015) state that identifying how to treat and support people living with the consequences of cancer and its treatment is an under researched area of healthcare despite the significant impact for those affected. In the 2018 publication *Research Priorities for Living with and Beyond Cancer* (James Lind Alliance) the need for greater understanding of long-term consequences of cancer is highlighted.

A stratified approach to cancer follow-up care means that contact with cancer specialists is variable after treatment ends (Maher et al., 2018), so the everyday experiences of this group of people may not always be visible to cancer care clinicians. The use of primary care services has been shown to be higher for people who have had cancer, in particular those experiencing long-term consequences (Khan et al., 2011; Treanor & Donnelly, 2014). This

has implications for the required knowledge and skills of healthcare professionals working outside of oncology.

Foster et al. (2018) highlight the importance of generating high quality evidence on life beyond cancer to influence service provision. Secondary research has traditionally focussed on quantitative data, however systematic review of qualitative evidence is increasingly significant in informing policy and practice (Barnett-Page & Thomas, 2009; Booth, 2016; Noyes et al., 2011). The synthesis of qualitative findings requires in-depth, analytical engagement with the data and enables novel meaning beyond that of the single studies to be developed (Bearman & Dawson, 2013; Soilemezi & Linceviciute, 2018).

Much recent secondary research has focused on findings related to the experience of one particular consequence of cancer and its treatment, such as fear of recurrence (Almeida et al., 2019) or consequences as experienced by those diagnosed with a specific cancer type, such as colorectal cancer (Han et al., 2018). Le Boutillier et al. (2019) reviewed qualitative data on the experiences of those living with and beyond cancer across different cancer types, however their intention was to develop a conceptual framework therefore different from the review presented here. This systematic review seeks to synthesise primary research findings to deepen understanding of the holistic, everyday experience of people living with a range of long-term effects across different cancer types. The term holistic is used to describe a wide range of biological, psychological, social and spiritual experiences affecting the whole person (Doyle & Henry, 2014).

## **METHODS**

### **Research question**

What are the holistic experiences of adults living long-term with the consequences of cancer and its treatment?

The research question was developed using the SPIDER search strategy tool for qualitative evidence synthesis (Cooke et al., 2012). SPIDER assists in the identification of search terms relevant for qualitative work under headings; sample, phenomenon of interest, design, evaluation, research type. This approach has proven, in initial tests, to yield more sensitive

results than the quantitatively focused PICO tool when searching for qualitative research (Cooke et al., 2012).

### **Protocol Registration**

A protocol for this review was registered on the International Prospective Register of Systematic Reviews (PROSPERO) in August 2019 (PROSPERO CRD 42019142544).

### **Inclusion and exclusion criteria**

Eligibility criteria were developed in collaboration with the research team. Publication date was restricted to 2008-2019. This aligns with the establishment of the National Cancer Survivorship Initiative between NHS England and Macmillan Cancer Support in 2008 and therefore covers a period of interest in cancer survivorship. Only English language articles were included for practical reasons.

Primary research was included if it:

- focused on the holistic everyday experiences of people diagnosed with adult-onset cancer living with the consequences of cancer and its treatment. All cancer types were considered for inclusion.
- included participants who were all over 18 years old when diagnosed with cancer (or if this was not the case then relevant data could be distinguished from those under 18).
- included participants who were 12 months or more beyond completion of acute cancer treatment. This timeframe was used to ensure those living long-term after the treatment phase were identified for the study. Where time elapsed since completion of acute treatment was not reported, studies were included where participants were three years or more post diagnosis.
- used qualitative or mixed-methods research design.

Exclusion criteria were as follows:

- secondary research
- quantitative design.
- focused on childhood-onset cancer.

- focused on a single symptom or single consequence of cancer and cancer treatment as this did not reflect the aim of examining the general experience of living after cancer.
- focused on a specific intervention in relation to cancer survivorship.
- focused on those receiving acute cancer treatment.
- focused on those receiving palliative care or end of life care.

### **Search Strategy**

Initial scoping of the relevant literature and policy drivers demonstrated the need to source multi-professional evidence on this topic to reflect the multi-disciplinary nature of cancer care. Soilemezi and Linceviciute (2018) recommend using multiple, specialist databases to source multi-disciplinary research. To identify the relevant literature, searches were undertaken in electronic bibliographic databases, British Nursing Database, CINAHL, Medline and PsycINFO in July 2019. These databases were chosen to ensure the fields of nursing, allied health professionals, medicine and psychology were represented. Search terms were identified in the literature and tested and refined in an iterative process involving the research team and subject librarians. Search terms were combined using Boolean operators 'AND', 'OR' and 'NOT' to ensure a precise search (Dundar & Fleeman, 2017). Truncation was used to capture all possible endings of words, for example surviv\* was used to identify survivor and survivorship. Fig. 1 shows the search terms and operators used.

### **Figure 1: Search Strategy**

Use of standard index search terms may be unreliable in qualitative research and the descriptive nature of qualitative abstracts and titles means additional methods are required to identify qualitative research (Soilemezi & Linceviciute, 2018). Citation searching using Scopus and hand searching of reference lists were therefore used to ensure a comprehensive search.

After completion of electronic searches duplicates were removed and titles and abstracts were screened. Remaining papers (n=38) underwent full text screening to ascertain

eligibility. A 10% sample of the search results was reviewed by another member of the research team to ensure eligibility criteria were applied consistently.

### **Data Extraction**

Data extraction was guided by Noyes et al. (2018). An inclusive approach to data extraction was adopted and all information in the 'findings' or 'results' sections was extracted for subsequent analysis, not limited to direct quotations from participants (Noyes & Lewin, 2011). Inclusion of author interpretations alongside participant quotes can help to avoid loss of meaning (Armoogum et al., 2019) so supporting in-depth, faithful analysis.

### **Quality Appraisal**

Quality appraisal of the articles was undertaken using an adapted version of the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (CASP, 2014; Tanay et al., 2017). A lack of consensus on best practice quality appraisal in qualitative research exists (Majid & Vanstone, 2018; Thomas & Harden, 2008). Subsequently there is debate as to whether studies appraised as poor quality should be excluded, as exclusion may lead to the loss of potentially relevant findings and increase bias (Soilemezi & Linceviciute, 2018). Consequently, studies were not excluded, based on quality of methods, if the study met the eligibility criteria. All articles included in the review met the quality criteria except one (Clemmens et al., 2008), which did not detail ethical approval for the study. Whilst this represents a limitation of the study it may be due to reporting guidelines applied to the article. Quality assessment of the studies was reviewed by two members of the research team to ensure consensus. Details of quality assessment can be found in table 1.

### **Table 1: Quality Assessment of six studies included for review (CASP (2014) Qualitative checklist as adapted by Tanay et al., 2017)**

### **Data synthesis strategy**

Thomas and Harden's three-stage thematic synthesis approach (2008) was used to extract, analyse and synthesise the data from the primary research articles. All data labelled as 'findings' or 'results' were extracted and coded line-by-line using NVivo analysis software. Codes were reviewed and categorised to form descriptive themes based on commonalities. Descriptive themes were examined to find meaning beyond the original data and new,

interpretative, analytical themes were developed. Thomas and Harden (2008) note that the final synthesis and creation of inferences beyond those of the original data is fundamental in qualitative evidence synthesis but that it is also controversial as it is founded on the researchers' subjective viewpoints and interpretations.

## **RESULTS**

Searching of the electronic databases identified five research studies for inclusion. Hand-searching of reference lists revealed one additional paper. Citation searching in Scopus returned no eligible papers. Six studies were finally included for review. Results of the search are shown in fig. 2.

### **Figure 2: PRISMA flow diagram of search results (Moher et al., 2009)**

The six studies reported findings from a total sample of 83 participants who were all living long-term after treatment for cancer. Sample size varied from seven to 19 participants. Studies were conducted in the UK, USA, Taiwan and Norway and were published between 2008 and 2019. Details of included studies are shown in table 2.

### **Table 2: Summary of characteristics of six studies included for review (adapted from Tanay et al., 2017).**

Following line-by-line coding and development of descriptive themes, data were synthesised to generate analytical themes. This was done in collaboration with the research team to ensure consensus on the meaning of the data and themes. This synthesis stage of the thematic synthesis model produced three analytical themes with four subthemes, across the six studies, as illustrated in fig. 3:

1. Living with an altered sense of self.
2. Things are never going to be quite the same again: 2.1. The unexpected. 2.2. The uncertain.
3. Ways of coping with the unexpected and uncertain: 3.1. Drawing on internal resilience. 3.2. The influence and impact of external relationships.

### **Figure 3: Diagram of analytical themes**

## **Theme 1: Living with an altered sense of self**

Results showed that the holistic experience of living long-term after treatment for cancer is characterised by an altered sense of self. The participants' world-view, sense of personhood and identity were changed as a result of having cancer. Participants reported a changed way of being and for some this resulted in a more positive and appreciative outlook on their lives.

For some this shift was existential and brought about a renewed perspective.

*'A rebirth, a wake-up call, or a second chance at life'* (Clemmens et al., 2008, p. 900).

*'My illness has changed my way of being. I have become a very happy person.'*

(Drageset et al., 2018, p. 4).

*'It's made me not worry about silly little things, you know, arguments, why, cos it's trivial.'* (Llewellyn et al., 2019, p. 50).

The continued presence of the cancer experience, in the form of late and long-term effects, impacted on the participants' sense of personhood after treatment had finished. A transition in identity from cancer patient to cancer survivor was reported. Participants felt that a renewed appreciation for life allowed them to see benefits as a result of having had cancer and this supported adjustment to life as a cancer survivor.

*'Doris allows breast cancer to act as a propellant in her life, allowing Doris to overcome the role of a patient and successfully enter into survivorship.'* (Matthews & Semper, 2017, p. 1361).

The change in personhood was viewed favourably by some and seen as a gift of the cancer experience.

*'You'll never be that same person again. ...It does something to you physically, mentally, and spiritually. It brings a new light to your life.'* (Clemmens et al., 2008, p. 900).



However, an altered sense of self was not always associated with positive changes and some participants spoke of the loss of their previous selves and lives in terms of ruination and fear.

*'I knew life was never going to be the same again. To me I feel a void...a fear.'*

(Clemmens et al., 2008, p. 900).

*'The radiation pretty much killed me...has ruined my life.'* (Clemmens et al., 2008, p. 901)

Changes in body-image and appearance had a detrimental effect on women's emotional relationship to their bodies. Accommodating changes in appearance had implications for day-to-day activities, such as choosing appropriate clothes to hide the visible effects of cancer treatment.

*'I am mindful of my appearance, and I am therefore in pain. I feel that I am very unhappy every day.'* (Fang & Lee, 2016, p. E43).

*'Shopping was very complicated. I had to buy clothes that had special sleeves.'* (Llewellyn et al., 2019, p. 50).

It appeared that both the experience of living through cancer and the ongoing long-term and late effects kept cancer present in the participants' lives. The benefit or harm felt by participants varied and the experience was not universally negative or positive. The following two themes will illustrate factors which influenced this altered sense of self and ways in which individuals coped with the shift in their everyday lives.

## **Theme 2: Things are never going to be quite the same again**

The altered sense of self was linked to the experience of a cancer diagnosis and treatment and the continuing presence of cancer in the form of a residual, long-term burden. The physical and psychosocial consequences of cancer and its treatment were described across the studies as ongoing and relentless (Matthews & Semper, 2017; Treanor & Donnelly, 2016) and were characterised by two subthemes; the unexpected and the uncertain.

### **Subtheme 2.1: The unexpected**

Participants felt that the potential consequences of cancer and its treatment were not explained to them by healthcare professionals during the acute care phase. The idea that some elements of the cancer experience would remain with participants beyond the end of their treatment was not anticipated and this realisation was stark for some.

*'Information about what I could expect of bodily ailments, such as lost energy, could have given me more sense of mastery and control. I would have been better prepared.'* (Drageset et al., 2018, p. 4).

*'With the exercises, you know, I said, oh, how long to I have to do these, and, you know, the nurse said, "for life", you know, for life, and that makes you realise that, you know things are never going to be quite the same again, you know.'* (Llewellyn et al., 2019, p. 50).

The abrupt end to regular contact with cancer care professionals and reduction in levels of ongoing support once treatment ended led to feelings of abandonment, described by one participant as a "smack in the face" (Matthews & Semper, 2017, p. 1359).

*'Suddenly from all this contact, which kind of accumulates because you're ... suddenly you're going in every day. And then suddenly it's absolutely nothing.'* (Llewellyn et al., 2019, p. 51).

*'There was like no ... no closure of that whole big relationship ... it was like oh, alright I'll go home now. It was kind of shocking really.'* (Llewellyn et al., 2019, p. 51).

A range of unanticipated physical and psychosocial consequences were reported which impacted upon quality of life. Participants experienced chronic physical symptoms which curtailed everyday activities and this reduction in physical ability had negative psychological implications.

*'If there are many things to do [but] this shoulder on this side is in pain I cannot get up to that window to clear it because now I have foot pain.'* (Fang & Lee, 2016, p. E43).

*'I was happy and had a great work capacity. Now, I have lost that joy of life and creative energy. It is both physical and psychological. I can't manage to participate at full tempo anymore.'* (Drageset et al., 2018, p. 4).

## **Subtheme 2.2: The uncertain**

Findings showed that those living beyond cancer faced continuing levels of uncertainty. This uncertainty was linked to a heightened awareness of their own mortality as a result of a cancer diagnosis. The fragile and temporary nature of life was acutely felt and future lives became less tangible than before. Comparison with other cancer patients led to superstition and a sense of a finite amount of luck to go around. This represented a way in which to make sense of an uncertain future.

*'It's the not knowing is the biggest thing, where the future lies with it.'* (Treanor & Donnelly, 2016, p. 340).

*'Well, the, the sudden thought of, you know, mortality, really (laughs), you know, how long did I have, you know.'* (Llewellyn et al., 2019, p. 49).

*'And the day I had my operation there was three of us went down and the other two girls died. Not right away, but they died, and sort of at the beginning you were thinking it must be my turn now.'* (Treanor & Donnelly, 2016, p. 341).

The uncertainty of the future was linked to a fear of disease recurrence, this was a prominent finding across all studies. Anxiety in relation to recurrence was a constant concern heightened by certain events, such as follow-up appointments and the anxiety did not necessarily diminish the further away individuals were from completion of treatment. The medical milestone of five-year survival was significant in reducing anxiety regarding recurrence in some, but notably not all, participants.

*'Sometimes, my thoughts just ran wild...which basically are...how long can I survive? When will the relapse occur? What should I do...to alleviate this excruciating pain? If there was some illness in one place of my body I would just say "Oh has the cancer migrated to that place?'* (Fang & Lee, 2016, p. E42).

*'One never knows if, or when, the cancer returns. I'm quick to call my RGP [Regular General Practitioner] to be checked. Feels good.'* (Drageset et al., 2018, p. 5).

The impact of living day to day with the unexpected and the uncertain consequences of cancer caused a shift in mindset and activities which permeated the experience of returning to everyday life.

### **Theme 3: Ways of coping with the unexpected and the uncertain**

The ongoing burden of cancer experienced by participants led to the development of coping strategies. Participants described a range of practical, social and psychological mechanisms they employed to help them to cope. Analysis of the data revealed an internal and an external life. Participants drew on internal resources to remain positive and external relationships with healthcare professionals, family and friends had a significant impact on emotional wellbeing.

#### **Subtheme 3.1: Drawing on internal resilience**

Participants demonstrated an internal resilience that helped them to cope. Actively and consciously seeking out positivity was a prominent theme. This included engaging in positive activities and embodying a positive outlook.

*'Going to the night classes and doing the gardening and the woodwork and all, because I felt I needed to do that. I wasn't going to sit here all day, every day...'*  
(Treanor & Donnelly, 2016, p. 343).

For some, this meant avoidance of people who were viewed as a negative influence.

*'I have someone in my family who is not particularly positive, but it doesn't bother me. I prefer to associate with those who are positive.'* (Drageset et al., 2018, p. 5).

Participants often kept troubles and negative thoughts to themselves, displaying emotional stoicism around family, friends and healthcare professionals. They shouldered both physical and psychological burdens alone, minimising the importance of their feelings and worries. For some the fact they had survived cancer took away any legitimacy to complain.

*'I can't moan about the treatment whatsoever and I never would because they saved my life because that meant a lot and it still does!'* (Matthews & Semper, 2017, p. 1359).

Others described shielding those close to them from painful truths and dismissing their own concerns.

*'Yeah. Because the other thing is I, I didn't want my friends to, to know how awful I felt.'* (Llewellyn et al., 2019, p. 49)

*'I haven't mentioned to anybody really... I'm sure a lot of people have the same worries.'* (Treanor & Donnelly, 2016, p. 341).

Not sharing their complaints was also a way to seek normality and distance the cancer experience.

*'I wanted to be me, I wanted them to, to feel that I was normal me, you know. And not for them to feel too bad for me.'* (Llewellyn et al., 2019, p. 49).

Seeking good health for the future was another strategy for coping, this was associated with reducing risk of disease recurrence and feeling active and engaged. Healthy behaviours and lifestyle changes were adopted.

*'Ah we are scared of relapse, so we try to eat some alkaline items.'* (Fang & Lee, 2016, p. E43).

*'We must exercise; otherwise, you just lay there or sit there, which cannot be good.'* (Fang & Lee, 2016, p. E43).

### **Subtheme 3.2: The influence and impact of external relationships**

Participants spoke about the impact that living with the consequences of cancer had on their relationships and also the influence that others had on their emotional wellbeing. Living beyond cancer left participants emotionally vulnerable to the reactions of others. Participants highlighted the need to be understood and treated sensitively by those close to them and healthcare professionals.

*'I remember I became a little provoked. People don't know what you have been through when they say, 'Ok, but now you have completed the treatment, so now everything's fine!' Because all is not well.'* (Drageset et al., 2018, p. 5).

*'I had one really strange experience which my friend who I've known since I was six...she couldn't come anywhere near me. Which is really weird.'* (Llewellyn et al., 2019, p. 51).

*'I need to know that, when you look at me, you understand who I am and that we can focus on a level that will make me feel comfortable with you.'* (Clemmens et al., 2008, p. 899).

Cancer and its consequences impacted upon relationships with family. Spouses took on caring roles and participants' ability to care for others was reduced.

*'My husband's very good. He can talk me through things. He would say 'Worrying about something is only going to make it worse. Worrying doesn't do you any good.'* (Treanor & Donnelly, 2016, p. 340).

*'I mean being with the grandchildren...and I hate not being able to put my arms out when they run.'* (Llewellyn et al., 2019, p. 50).

Healthcare professionals played an important role in supporting participants during treatment and the loss of regular contact afterwards impacted significantly on participants. Healthcare professionals, in particular specialist nurses, had provided reassurance and information during acute care and without this, participants felt isolated.

*'They were just brilliant. I think the breast care nurses were invaluable.'* (Matthews & Semper, 2017, p. 1360).

*'We patients need the attention of the doctors. If the doctor cares for me, I feel okay; thus, I am not afraid when the doctor is present.'* (Fang & Lee, 2016, p. E44).

Participants reported that better communication with their primary care team after treatment ended would have alleviated anxiety and they recommended more continuity of care.

*'It would have been quite nice for when you'd finished your treatment to sort of be handed onto the GP more, I suppose more or less for reassurance ... and to sort of say right well you know the hospital bit's finished now but you can always come to me.'* (Llewellyn et al., 2019, p. 51).

Participants also stated that having contact with other cancer survivors reduced feelings of isolation whilst promoting normality.

*'And it was like "Oh so, I'm not on my own then" ...Um and then you talk to the others, and they say "No that's normal.'* (Llewellyn et al., 2019, p. 51).

## **DISCUSSION**

This systematic review aimed to identify, collate and synthesise the evidence in relation to the holistic experience of living long-term with the consequences of cancer and its treatment. Thematic synthesis (Thomas & Harden, 2008) was used to appraise and analyse the primary qualitative evidence identified on this topic. The main finding was that the experience of living long-term after cancer is characterised by an altered sense of self. This existential change is associated with the ongoing burden of the consequences of cancer and its treatment. Internal strength and external relationships influence people's ability to cope with life after cancer.

Themes identified by Le Boutillier et al. (2019) in their systematic review demonstrate some overlap with themes presented here. Their results describe the adversity of living with and beyond cancer which aligns with theme 2 of this review, 'things will never be quite the same again'. The influence of healthcare professionals, the physical and psychological consequences and the impact on sense of self are all represented in their review and this supports the findings presented here.

Similarities can also be drawn with a meta-review of systematic reviews by Laidsaar-Powell et al. (2019) who found a lack of evidence on cancer late-effects and under representation of cancers other than breast and gynaecological in the literature. This current review seeks to describe the global experience of living after cancer rather than focusing on one cancer type or one aspect of survivorship. Laidsaar-Powell et al. (2019) also aimed for a comprehensive overview of cancer survivorship. Themes identified in the meta-review are also seen in this review, in particular late-effects of cancer, fear of cancer recurrence, and coping strategies and resilience. These were minor-themes in the meta-review and the authors suggest these as potential areas for future investigation.

The experience of living beyond cancer and its treatment has a significant impact upon identity and personhood. Participants in the studies reviewed here spoke of shifts in their perceptions of themselves and of their lives and relationships. This change was viewed both positively and negatively, some experienced a renewed appreciation for life, whilst others

were left with an ongoing burden. Therefore, both the significance of the impact of cancer on sense of self and the diversity of reactions should be acknowledged to promote understanding.

The findings of this review show that there is a lack of support once acute cancer treatment is completed. Regular contact with cancer specialists ends suddenly, resulting in feelings of isolation. People have to contend alone with unexpected physical and psychological consequences and an ongoing fear that their cancer will recur. Le Boutillier et al. (2019) also recognise the stress of the post-treatment phase, highlighting the ever-present fear of recurrence once the treatment ends. Greenfield (2017) suggests this fear can be paralysing, which has implications for ongoing quality of life and wellbeing. A lack of information about what to expect after cancer treatment is identified in this review. Consequences were not anticipated or prepared for and participants would have welcomed more information from healthcare professionals before treatment ended and improved continuity and communication from primary care services.

Despite the reported lack of preparation people did find ways in which to cope with the impact of having had cancer. Internal resources and emotional strength were important in promoting a positive outlook. The ability of those around them to influence their experience was recognised. The findings show that healthcare professionals have the potential to play a bigger role after treatment ends and that peer support may be beneficial in navigating life beyond cancer. Foster et al., (2018) highlight a research gap when considering preparation for life after cancer treatment, consideration of how best to improve preparedness is required.

### **Limitations**

Only six papers were identified after a comprehensive search of the literature and, despite all cancer types being included in the eligibility criteria, four of the six papers explored the experience of breast cancer survivors only. Only one paper included the views of male cancer survivors. This limits the transferability of the findings.

Of the six papers reviewed, one was American, one from Taiwan, four studies were conducted in Europe with three being in the UK. Differences in cancer care delivery between countries may limit the transferability of findings. However, the data synthesis identified an



ongoing burden after cancer and this was represented across all papers, as was the need for information to prepare for life after cancer making results of interest internationally.

Thematic synthesis relies on the reviewer's interpretations of the extracted data, both primary quotes and primary author interpretations. At each stage of analysis and synthesis meaning was further inferred by the reviewer, moving beyond the original meaning. Whilst the creation of new meaning is the aim of thematic synthesis the influence of the reviewer on the results must be acknowledged.

### **CLINICAL IMPLICATIONS**

A prominent finding of this review was the persistent presence of the cancer experience in the lives of survivors long after treatment had ended. This is important for healthcare professionals to recognise. In particular those working outside of a cancer care setting as the needs of this group will likely need to be met by primary care professionals rather than cancer care specialists. Another important aspect to note is the lack of preparedness for life after cancer that people felt as they completed their acute treatment. With this knowledge professionals working in cancer care can improve information giving and support leading up to the end of treatment and facilitate consistency of care during transition to primary care services. The need for continuity in care after cancer is highlighted in UK policy and across Europe and links directly to the findings of this review (Albrecht et al, 2017: Macmillan Cancer Support, 2015).

### **CONCLUSIONS**

The findings show that cancer continues to play a significant role in how people live long after diagnosis and treatment, yet effective preparation and ongoing support for this phase of the cancer pathway is lacking. The holistic impact of living beyond cancer is profound and has implications for long-term wellbeing. Healthcare professionals should be aware of the identified gaps in service provision and the ongoing holistic needs of this group so that care and services can be tailored to improve the experience of this growing group of people. Further research should seek to improve understanding of the impact of the consequences of cancer across a wider range of cancer types and explore the services required to meet needs effectively.

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### **Figure Legends**

**Figure 1: Search terms and Boolean operators used in electronic database searching.**

**Figure 2: Results of search strategy.**

**Figure 3: Diagram showing analytical themes generated during thematic synthesis.**