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Title: 'Still living with it even though it's gone': Using Interpretive Phenomenological Analysis to explore shared experiences of living with and beyond breast, prostate, and colorectal cancer.

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INTRODUCTION

Living with and beyond cancer is a highly personal experience that can affect many parts of an individual's life (Independent Cancer Taskforce, 2015). Advances in prevention, early detection, and treatment means that people are now living with the effects of their cancer diagnosis for longer, and living with and beyond cancer is becoming an increasingly common experience (Foster and Fenlon, 2011). The experience of living with and beyond cancer moves away from cancer survivorship (which implies a definite conclusion to cancer) as the dominant discourse in cancer care (Foster et al, 2018). Although the concept of living with and beyond cancer is evident in international policy and literature, supporting people to live with and beyond cancer is complex because there are inconsistencies in understanding (Le Boutillier et al, 2019). Research is uncovering individual experiences of those living with cancer (Donovan and Flynn, 2007, Burles and Holtlander, 2013), but it has been argued that this idiographic nature of living with and beyond cancer (i.e. an individual person, with one type of cancer, in their specific context) has limited impact and reach (Larkin, 2019, Palmer, 2010). Phenomenology is concerned with part-whole relationships; that is, identifying the essential structure of experiences and the constituent parts that go to shape those experiences (Tomkins, 2010). A recent systematic review and narrative synthesis that developed an overarching conceptual framework to describe the patient experience of living with and beyond cancer has gone some way to identifying shared experiences (Le Boutillier et al., 2019). However, primary research that focuses on exploring how individual experiences (the parts) may be relevant to others who are living with and beyond cancer (the whole) is limited, with only four of the 73 included studies focusing on experiences across cancer types (Foley et al., 2006, Hubbard and Forbat, 2012, Grimsbo et al., 2011, de Guzman et al., 2013). It is important that shared experiences of living with and beyond cancer are identified in order to design effective services that address common unmet needs, to inform quality improvement, and to ensure that cancer support and resources are allocated effectively (Tsianakas et al., 2012a). Understanding shared experiences of those

who are living with and beyond cancer informs the provision of care across the cancer experience, by identifying who needs what support, and how this support is best delivered (Foster et al., 2018). Providing services built on shared experience also addresses the need to reduce variation in treatment, outcomes and experience within and between different cancer types (Independent Cancer Taskforce, 2015).

The primary aim of this study was to contribute to the understanding of what it means for individuals to live with and beyond cancer. The second aim was to complement idiographic knowledge with multiple perspectives from a particular cohort of participants who are living with or beyond breast, prostate, or colorectal cancer to explore how individual experiences may be relevant to others.

METHODS

Study design

The study was designed in two stages: 1) semi-structured interviews were conducted to explore individual experiences, and 2), focus groups were used to explore how individual experiences may be relevant to others who are living with and beyond cancer. The study used interpretive phenomenological analysis (IPA) as described by Smith et al. (2009). IPA was selected for this study because it focuses on exploring the meaning of, and how people make sense of their life experiences (Smith et al., 2009), and has been used successfully in other research investigating lived experiences of cancer (Maguire et al., 2014, Williams and Jeanetta, 2015, Phillips et al., 2017, McGeechan et al., 2018).

IPA is based on phenomenology, that is the study of the lived meaning of an experience, and hermeneutics, the art and science of interpretation or meaning. IPA follows an idiographic approach with detailed and nuanced analysis of each case before examining the convergence and divergence between participants' experiences (Smith et al., 2009). IPA studies have typically been conducted on small sample sizes to allow for detailed case-by-case analysis of individual experiences about the perceptions and understandings of each

participant (Smith et al., 2009). However, focus groups are now emerging in IPA studies and are used to extend the commitment to idiography by combining and co-constructing lived experience (Larkin, 2019, Phillips et al., 2016, Palmer, 2010, Githaiga, 2014). To our knowledge, this is the first study that extends the use of IPA methodology by integrating interview and focus group data, and by exploring the concept of living with and beyond cancer across cancer types. The study design is illustrated in Figure 1.

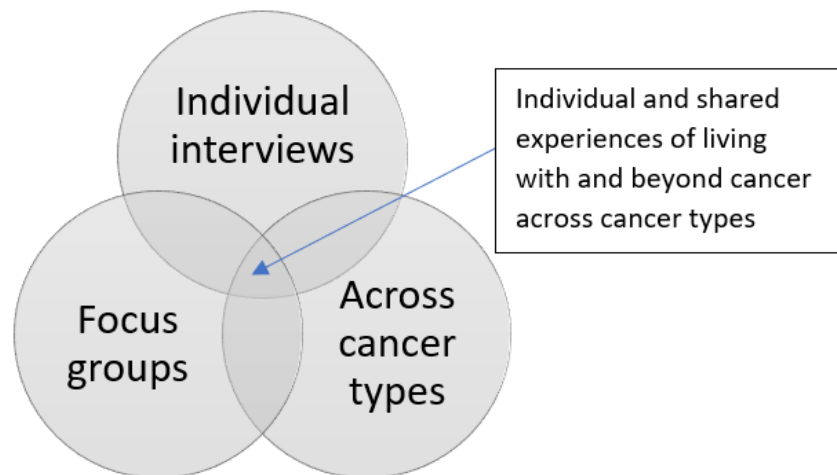


Figure 1: Study design that combines individual and group-level data across cancer types

Data collection

Data collection was conducted at Imperial College Healthcare NHS Trust (ICHT). In stage 1, eighteen semi-structured interviews were carried out with patients who had received primary treatment for breast (n=6), prostate (n=6) or colorectal (n=6) cancer. In stage 2, six focus groups with different patients who had received primary treatment for breast (n=13), prostate (n=5) or colorectal (n=8) cancer were conducted. The decision to explore the lived experiences of breast, prostate and colorectal cancer was made because they are among the most common cancers in the UK (Independent Cancer Taskforce, 2015).

Participants were selected on the basis that they could offer a particular perspective on living with and beyond cancer (Smith et al., 2009) - those who had received primary treatment for breast cancer, prostate cancer and colorectal cancer and who had been risk-stratified to low-

risk open-access follow-up, also known as self-managed stratified follow-up. The aim was not to have a completely homogenous sample as is consistent with some IPA studies so that convergence and divergence could be examined within the sample. Participants were over 18, proficient in English, and were based in London or able to travel to an ICHT site.

Potential participants were first approached by a cancer support worker, and subsequently recruited by the lead author via the telephone, email or face-to-face. Informed consent to enter the study was sought from each participant only after a full explanation and information leaflet was given and time allowed for consideration. Signed participant consent was obtained. The right of each participant to refuse to participate without giving reasons was respected. All participants were free to withdraw from the study up to 14 days after participation without giving reasons and without prejudicing further treatment. The anonymity of participants is preserved here through the use of pseudonyms (Smith et al., 2009).

In stage 1, interviews used flexible open-ended in-depth questions for early data collection to offer participants the opportunity to share their stories, thoughts, and feelings and to gather rich, detailed first-person accounts of their lived experiences of living with and beyond cancer. The interview schedule asked participants to describe what it means to live with and beyond cancer, in their own words, and explored factors that support (or hinder) people to live with and beyond cancer and is included in Online Data Supplement (ODS) 1. Interviews were conducted across ICHT sites by the lead author, lasted around one hour, and were audio recorded and transcribed verbatim. Where requested, transcripts were returned to participants for comment and correction.

In stage 2, early findings from the interviews were presented to a wider group of participants in 90-minute focus groups for further theoretical exploration. The aim was to generate discussion by providing examples of what it might mean to live with and beyond cancer. Separate focus groups were conducted with patients who had received treatment for breast, prostate or colorectal cancer to allow perspectives to be shared with others with similar

treatment experiences (Morgan, 1997). Focus groups were led by CL, and were audio recorded and transcribed verbatim. The focus group topic guide focused on exploring whether the interview findings were representative to others as a shared experience of living with and beyond cancer and is included in ODS 2.

Reflexive notes were kept after each interview and focus group, and during the interpretive stages of analysis, and a particular focus was given to the role of the researcher in co-creating the meaning of participant's experiences (Smith et al., 2009).

Data Analysis

Interpretive phenomenological analysis of the data was undertaken using the procedure outlined Smith *et al* (2009), whereby analysis is grounded in accounts of experience (Smith et al., 2009). IPA is an iterative inductive process that moves back and forth through various stages to ensure in-depth and systematic examination of participant's experiences. A layered approach to analysis was adopted to explore *the parts*; that is individual idiographic accounts, and how individual idiographic accounts were relevant to others with breast, prostate, or colorectal cancer experiences. The analysis was then extended to explore *the whole* by investigating if and how group accounts across cancer types were relevant to others who are living with and beyond cancer.

Data analysis began with individual-level case-by-case repeated re-reading of interview transcripts and re-listening of sound files to become immersed in the data. This was followed by note-making of descriptive, linguistic, and conceptual observations to produce an initial analysis of each interview transcript. NVivo QSR International qualitative analysis software (version 11) was used to manage the data in a way that supported data analysis (International, 2018). Line-by-line open coding was conducted, and individual extracts were coded under one or several themes to fully capture their meaning. An initial coding frame was drafted where themes were developed and connections across themes were explored.

Thematic similarities that were identified between interview participants were drawn together to form super-ordinate themes.

The second phase of data analysis involved reading and re-reading each focus group transcript to make sense of individual experience as well as to make sense of the participants' attempts to make sense of others experiences within the group. This involved moving between individual focus group participant coded accounts and the shared group narratives. Considerations were given to how participants agreed or disagreed, and how participants supported each other to share their stories. Effort was taken to explore where group elements contributed to developing themes as well as how the themes were meaningful to the members of the group (Tomkins, 2010, Palmer, 2010).

Cross-case analysis of each interview and focus group was used to code themes, to identify patterns, and to develop a final coding framework representing multiple perspectives. To further explore relationships in the data, interview and focus group interpretations were re-considered by conducting an additional iterative loop (Love, 2020). The iterative loop involved tabulating themes across data sources, allowing for individual and group-level comparisons of the final coding framework. This process also ensured the collective-level interpretation was not privileged over the individual (Tomkins, 2010).

Data analysis occurred concurrently with data collection. The lead author directed the analysis. Multiple coding (CB and SA) was undertaken to reflect on and enhance the awareness of the coding approach, and to enhance rigour (Mays and Pope, 1995).

Ethical approval

The study was funded by Macmillan Cancer Support and hosted by Imperial College Healthcare NHS Trust. Ethical approval was obtained from the West Midlands - Black Country Research Ethics Committee and the Health Research Authority (REC reference 17/WM/0127).

RESULTS

Participants

A total of 18 people with personal experience of living with and beyond cancer participated in interviews, and an additional 26 people who are living with and beyond cancer participated in focus groups. Their characteristics are shown in Table 1.

Insert Table 1 here

The mean age of participants was 67.0 years (range 38-82), and time since diagnosis ranged from less than one year to seven years. ODS 3 details additional interview participant characteristics and ODS 4 details additional focus group participant characteristics. Of those people contacted by the researcher (CL), 90% agreed to take part in an interview (two people declined) and 60% agreed to take part in a focus group (17 people declined participation).

The findings presented here demonstrate the ways in which accounts from multiple perspectives relate to one another, how differences can co-exist, and the paper explores how the multiplicity adds to the analysis. The super-ordinate themes to emerge from the data were: *the cancer shock*, *managing cancer and getting through*, and *getting over cancer*. Participants' narratives focused on temporal stages of living with and beyond cancer so each of the themes can be mapped into dealing with i) diagnosis, ii) treatment or iii) life after treatment. Online data supplement (ODS) 5 provides the full coding framework and Figure 2 provides a visual representation of the themes.

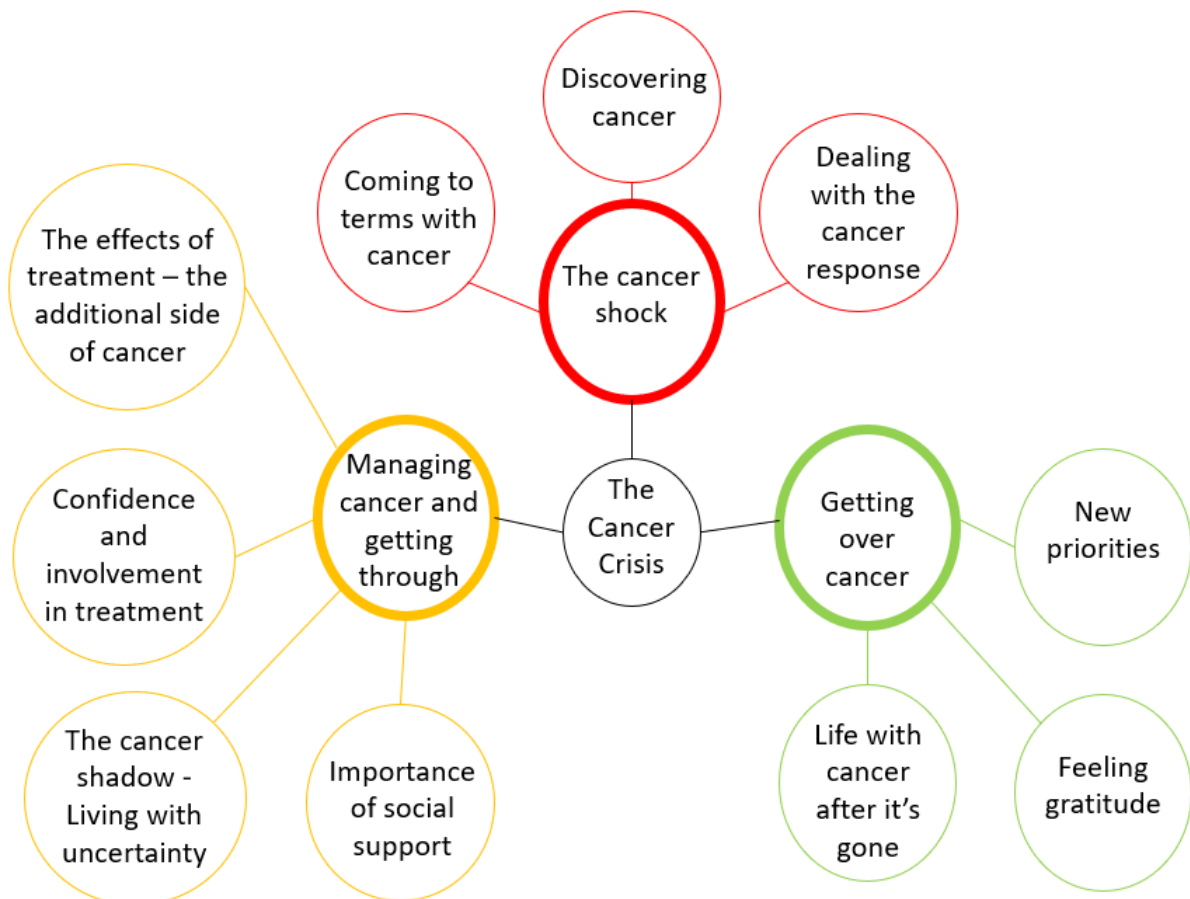


Figure 2: Visual representation of themes

Participant accounts detailed how the experience of living with and beyond cancer starts out with cancer consuming a large space in life, and as time passes and treatment progresses, the cancer space becomes smaller and less important. However, it was noted that this is not always a straightforward process, often with *'ups and downs'* (Elliott, colorectal group), and where cancer *'is beside me... [I'm] carrying it... I'm not always looking beyond it'* (Helen, breast group). Rosa explained how *'it's from the fear to the acceptance and then the cloud with the concern of recurrence hanging over her'* (Rosa, breast interview).

For others, cancer no longer took any place in their lives; their experience of living with and beyond cancer described as *'a short period of my life that has been on hold [and] just a blip at that time'* (Rachel, breast interview); *'an episode which is over and done with'* (Sebastian, colorectal interview); and *'a compartmentalised part of life'* (Helen, breast group).

Complementing idiographic knowledge with multiple perspectives

While individual accounts of living with and beyond cancer detailed features specific to each person's experience, focus group discussions illustrated how participant life worlds interact and overlap, and emphasised that specific features are connected to shared perspectives between individuals and across cancer types. The range of breadth and depth captured in the focus group data contributed to and complemented the content of the themes. The following quote also illustrates the cohesion, support, and therapeutic nature of sharing experiences in a focus group interaction:

Interviewer: *'We're going to start to wrap up now.*
Maria: *Yes, well, I enjoyed it, thank you for having me.*
Sienna: *When are we going to meet again?*
Olivia: *We would want to meet again.'*

Table 2 illustrates the distribution of super-ordinate themes across cancer types and between individual and group-level data. Quotes that illustrate shared focus group experiences across cancer types are included in ODS6, and ODS7 goes on to illustrate quotes across interview (idiographic) and focus group (collective) data for the breast cancer group.

Insert Table 2 here

Theme 1: The cancer shock

The experience of discovering breast, prostate or colorectal cancer is a time of crisis. Interview participants spoke about the *'terrible shock [and] sense of outrage'* (Samuel, prostate interview) of receiving a cancer diagnosis, and of being forced to consider a threat to their life:

'The first thing you think is, am I going to die from it?... When they tell you, 'you got cancer', it's like you got a death sentence in a way. You think God, will I survive? (Matthew, prostate interview).

Focus group participants built on the narrative and went on to discuss the loss of control and sense of disbelief at finding out about their cancer diagnosis, sharing stories of how *'your whole world is turned upside down and the bottom of your world drops out'* (Olivia, breast group). The stigma and sympathy associated with a cancer diagnosis was also a shared concern across focus groups. Having prostate or colorectal cancer was described as *'embarrassing'* (Leo, prostate interview; David, colorectal group) and some with breast cancer did not want to be seen as a *'cancer patient'* (Norah, breast interview; Annabelle, breast group).

The cancer shock also involved coming to terms with having breast, prostate, or colorectal cancer. This was described as less complicated for those who received an early diagnosis, and who received their diagnosis in the right way at the right time. For Jack, it was the reassurance from health staff that everything would be okay:

'I am lucky that mine was caught early, dealt with, done and dusted... What I do remember, the consultant said, well I can tell you now, you have got prostate cancer. That's the bad news. The good news, he said, it isn't going to kill you. I can tell you that now. I thought, well that is good news, so from there I am completely relaxed about the whole business' (Jack, prostate interview).

The right way for other participants was the need for a practical conversation about what happens next:

'The doctor said, 'Well the biopsy came back and its cancer'. And he was fantastic, he told me everything, but then the breast nurse takes you out to another room and starts all this hand on shoulder thing, and it's almost like she was burying me there. And I'm thinking I don't need this, I really needed someone to just tell me point blank this is what's going to happen next, this is what you need, this is what the next step is' (Annabelle, breast group).

Each of the cancer groups spoke about how their mindset was instrumental in how they accepted and adjusted to their diagnoses: *'It's a person's attitude and if you've got that attitude, "I'm going to sort this, I'm going to beat it"'* (George, prostate group).

Disease knowledge and experience also influenced participants' ability to come to terms with their diagnosis. Other health needs often had more prominence in people's lives, such as heart disease and diabetes:

'I mean, I get more follow up reaction from my heart bypass operation which was done in 2003. I am still arguing about whether I should take my statins. I mean, that's much more part of my life – living with and beyond heart problems would be much more part of my life than cancer... 'I have never seen it as the big awful big C... you do not have to die anymore' (Jack, prostate interview).

Cancer was also less of a shock for participants who knew people who had survived cancer and had seen friends go through it.

'I have two very close friends and one other friend who have had mastectomies, they are all doing incredibly well, I mean I think probably all of them have survived 10 years, and so they are a very good role model for me. I mean with 2 of them I was very involved with their treatment, and recovery. So, it isn't a subject I hadn't thought about' (Coral, breast interview).

Finding out as much as possible about cancer and treatment options supported participants' ability to adjust to their cancer diagnosis. Sources of support included: information from clinical staff, online, via Macmillan Cancer Support Centres, Maggie's Centres, other local cancer centres and charities, and peer support:

'I think when you talk to people, they tell you their experience and then you get a bit of satisfaction thinking right he had cancer, he did this, and he is better. Let me do it, let me try' (Ruth, colorectal interview).

Participants also stated how they are forced to consider the impact on others when finding out about their breast, prostate, and colorectal cancer. Norah chose to conceal her diagnosis because she did not want people to feel sorry for her:

'I didn't want to show my weakness because cancer is weakness, negative in life. I don't want to show negative things in life. I don't want them to say, 'sorry you have cancer' I don't want their sympathy' (Norah, breast interview).

For some, sharing the diagnosis was a relief that allowed some individuals *'to look a bit more forward'* (Irene, breast group) and for others it meant that the experience was less solitary stating *'we're in this together'* (Felicity, breast group). Others preferred not to share their diagnosis reporting a *'sense of control if I carry it with me'* (Helen, breast group).

Narratives shared in individual interviews generated more codes around coming to terms with cancer, while focus groups provided a depth to the discussion with participants exploring the range of shared influences among the group. Focus groups extended the discussion around whether to conceal or reveal, reporting a desire to protect others from burden, feeling scared for others and needing to stay strong to support others. Discussions also centred on the need for outside support for family members at the time of diagnosis:

'My husband never said anything, but I know he is feeling it. He is feeling it, he is carrying it with me, at the same time. I told the children, we have got two daughters, I told one but the other one is not well, so I couldn't tell her, because that would worry her too much' (Emma, colorectal group).

Theme 2: Managing cancer and getting through

Managing cancer (and getting through) was described as *'just something you have to slog through'* (Coral, breast interview). Focus group participants spoke about the sense of urgency that came following diagnosis, and the fast pace at which they were engaged with the cancer treatment pathways.

'So, once everything's happening, you're just going with it, there is no other way, you can't step back and think for long because this thing develops quick, you know, so you have to really make up your decision really quickly as you go to appointments and everything' (Annabelle, breast group).

Interview participants provided greater detail and went on to speak about their confidence in health staff, being involved in health care planning, and being informed about treatment options as a support for managing cancer:

'They basically put together a plan and said, 'right well, radiotherapy for however many months...' it was surgery at that point and chemo afterwards, bang, bang, bang, bang, bang. So, within 18 months or whatever it was, diagnosed, and out sort of thing. So, you couldn't really ask for more than that' (Paul, colorectal interview).

For other interview participants, the dependence on health care and being *'completely at the mercy of medical staff'* (Matthew, prostate interview) left a feeling of being lost, of feeling uncertain, and of feeling *'like you are a number in the system'* (Alice, colorectal interview) or

of being excluded from conversations about care options; *'we talked about chemo but dismissed it – well we didn't really talk- I said to my consultant – this was my one criticism... I wasn't really given much other options and I had looked into what the other options were'* (Jack, prostate interview).

Managing cancer also involved dealing with the various physical, emotional, social, functional, and financial effects of treatment. Treatment was described as *'a disgrace to the body'* (Ruth, colorectal interview) and the effects of treatment were described as *'the additional side of cancer'* (Martha, breast group). Interview and focus group narratives focused on sharing the side effects of cancer treatments. Common experiences included tiredness, nausea and sickness, brain fog and impaired memory, neuralgia, poor sleep, fear of being cut short, and impaired sexual function. Scarlett, living with a colostomy bag had a profound impact on her life that left her feeling low and isolated:

'It's a really bad experience. I was active all the time... and I had to stop working, it was awful, and also with my social life, I had to stop. Most of the time I had to be home because I was really down and because [of] the bags. I was so embarrassed. I had so many accidents with the bags... the bags would open up, the smell it was terrible' (Scarlett, colorectal interview).

Thomas spoke about the impact of his prostatectomy:

'I did ask, 'how would this affect my sex life' ... He said, 'well, we will do whatever needs doing', and he did, and it has left me now, no sex life really' (Thomas, prostate interview).

For Amelia, managing cancer was influenced by a lack of support after being left to manage hormone therapy when radiotherapy ended:

'... and then your friends are, "Oh well, you've had your last [radiotherapy] appointment now" and so for me, I'm still actively in the middle of it but somehow the process has said, "You've ended it – okay you've got hormone therapy, but you're over with it now". I felt the system thought I was done with well before I thought I was actually over that immediate stage. I felt like I'd been chucked off a cliff or cut off, and I was still in the middle of it and the process was saying, "That's your last day of radiotherapy, you're done now" and that was quite a difficult thing' (Amelia, breast group).

Alongside managing the effects of treatment, participants described a persistent concern about recurrence, and of *'living under the cancer shadow'* (Rosa, breast interview). This meant that some

people felt like life was 'on hold' (Rachel, breast interview) while they remained under surveillance 'waiting for my graduation' (Rosa, breast interview). Interviews and focus groups described that the availability of peer support, faith-based support and social support was a helpful contributing factor when managing cancer:

'...make sure you have the support from your family and friends... that's the big thing and not to think you can manage it on your own' (Rita, breast interview).

Theme 3: Getting over cancer

Participants noted that their perspective of living with and beyond cancer changed with time. For some, cancer and the experience of cancer treatment became a second chance, and a prompt to enjoy life again; for others it meant accepting limitations and that life would be different:

'... everything has changed because this disease or illness changes your life. Now, I must accept that this is my destiny; I will have to live with it' (David, colorectal group).

Rosa felt that 'I am still living with it even though it's gone... it's an invisible thing' (Rosa, breast interview) and Helen stated: 'I have moved on with my life but taken my cancer experience with me. I'm a different person now' (Helen, breast group). Some participants felt they were back to living their lives as before, and others felt they were still surviving. Life after cancer was described by many as living your 'life as a result of treatment, not living with treatment, you're living as a result of treatment'. (Max, prostate group).

Rita questioned whether she might forget the impact of her cancer experience with time:

'I mean, more than 20 years ago I had a hysterectomy but mostly when I am asked my medical history, I tend to forget that, so I don't know if that would be the same for breast cancer as the time goes by' (Rita, breast interview).

Norah likened the crisis of cancer to other life experiences such as bereavement and loss. She explained how she had coped with divorce and parental death, and conceptualised cancer as another *different* time in life:

'So, everybody has different times in life. I divorced and I recover, and second probably, the parents die. So hard, cancer. So, time to time, life is like that' (Norah, breast interview).

Participants spoke about new priorities for life, and some felt thankful for their cancer experience and the support they had received. Matthew spoke about the confidence that he gained from dealing with cancer:

'I don't quite know how to say it, it's not a good thing that happened to me, but something that happened made me see things in a different way, in a better way... I see things in a different way now, a much more positive way. I am much more positive now than I ever was, definitely, when you come through this you've got to be positive. If I have come through this, I can come through anything' (Matthew, prostate interview).

DISCUSSION

The first aim of this study was to contribute to the understanding of what it means to live with and beyond cancer. The findings consist of three super-ordinate themes: i) *the cancer shock*, ii) *managing cancer and getting through*, and iii) *getting over cancer*. Participants used time-based narratives to construct their stories about living with and beyond cancer so each of the themes can be largely mapped onto dealing with i) diagnosis, ii) treatment or iii) life after treatment.

The findings compliment and align with existing literature on living with breast, prostate or colorectal cancer (Le Boutillier et al., 2019) (Rogers K et al., 2021). While lived experience narratives offer a linear account in keeping with the treatment timeline, psychosocial adjustment and transitioning is a dynamic process with ups and downs, peaks and troughs, and waves (Pascal J, 2010). A recent systematic review and narrative synthesis describes the lived experience of cancer from the patient perspective and identifies three inter-linked themes: Adversity, Restoration and Compatibility, resulting in the ARC framework (Le Boutillier et al., 2019). The three super-ordinate themes presented in our analysis can be accommodated by the ARC framework, offering a consistent understanding of the adjustment to living with and beyond cancer and reinforcing the usefulness of a framework for services (Smith, 2018, Hubbard and Forbat, 2012, de Guzman et al., 2013). For example, adversity is experienced in *the cancer shock* phase when dealing with the challenge of

receiving a diagnosis and a threat to life (Shaha and Cox, 2003, Ervik et al., 2010). Strategies used to confront the adversity include seeking information and *finding out all you can* (Obeidat et al., 2012, Boehmke and Dickerson, 2006). Equally, for some 'adversity' also happens during and after treatment (*managing cancer and getting through* and *getting over cancer*) where people describe having to deal with the effects of treatment and *where 'things are never going to be quite the same again'* ((Rogers K et al., 2021) p.5). For others, the treatment phase might align with 'restoration', with efforts being supported by *confidence and involvement in treatment, support from healthcare providers*, and social support (Ervik et al., 2010, Jonsson et al., 2010, Williams and Jeanetta, 2015, McGeechan et al., 2018). Jonsson et al (2010) describe the process of adapting to life after treatment as '*balancing a changed life situation*' (p.27) where people are *getting over cancer* (Jonsson et al., 2010). Like the 'compatibility' phase in the ARC framework, this highlights an altered sense of self and importance for some individuals to adjust to *life with cancer after it's gone* (Brennan, 2001, Rogers K et al., 2021).

The second aim was to explore multiple perspectives from people who have received treatment for breast, prostate, or colorectal cancer. Although experiences of living with and beyond cancer are well documented, this study extended the use of IPA by integrating interview and focus group data, in order to complement idiographic knowledge with multiple perspectives. The value of diverging from traditional IPA methodology has been illustrated by exploring how individual experiences (the parts) may be relevant to others who are living with and beyond cancer (the whole) (Larkin, 2019). Collective experiences have allowed an opportunity to enrich individual accounts by building a complex picture of the parts and the whole across cancer types. While individual accounts of living with and beyond cancer detailed specific features, similarities in lived experience across individuals and cancer types were also identified; 'the specifics are unique, but they are hung on what is shared and communal' (p.38) (Smith et al., 2009). We propose that individual accounts offer the

foundation for personalised supportive cancer care (the parts) and the shared experiences provide a central overarching scaffold for developing service-level provision that ensures cancer support and resources are allocated effectively.

Clinical implications

First-hand experiences contribute to the understanding of living with and beyond cancer and this knowledge can be used to address people's needs and to inform the design of support services, stratified pathways and goals of care (Independent Cancer Taskforce, 2015, Maher J et al., 2018). The findings confirm that living with and beyond cancer requires a continuum of care with the experience beginning at the point of receiving a cancer diagnosis and having no definitive endpoint; the disruption of illness means that life is adjusted, and people are forced to consider a 'new normal' (Costanzo et al., 2007). While it is vital that policy and practice initiatives continue to focus efforts on early diagnosis and treatment, it is also important to acknowledge and respond to cancer as a chronic condition that requires long-term supportive care (Rogers K et al., 2021). Therefore, an individualised and person-centred approach to care that is offered within an overarching framework of care, from diagnosis to life after treatment, is required to ensure improved long-term quality of life for people who live with and beyond cancer (Cappiello et al., 2007). Within this framework, a holistic approach that addresses physical, emotional, social, functional, and financial support needs, that supports adjustment and transition, and that promotes quality of life is also required (Independent Cancer Taskforce, 2015, Maher J et al., 2018).

Holistic assessments (such as the Holistic Needs Assessment in the United Kingdom) promote patient preference and offer the opportunity for clinicians to work in partnership with people who are living with and beyond cancer by offering supportive conversations on which to share decisions and to co-produce individualised care plans that address person-centred goals (Department of Health, 2012). This practice mirrors that of recovery support in mental

health services, where co-production is also emerging as a powerful model to support the active participation of individuals who use services (Le Bouillier et al., 2011, Batalden P, 2018). This equal partnership working between staff and patients enhances existing health systems, for example collaborating and involving patients in cancer multi-disciplinary team meetings (Soukup et al., 2020). As people focus more on living with cancer after treatment, the need for long-term management is also becoming increasingly apparent. The NHS long-term plan offers a comprehensive model of personalised care that promotes shared decision making and that empowers people by being involved in personalised care planning (NHS England, 2019). This requirement for ongoing personalised support mirrors that of other chronic conditions such as diabetes (Engstrom M.S. et al., 2016) and stroke (Burton C.R., 2000).

Research implications

The novelty and diversity of the research methods used in this IPA study allowed for different research roles and interactions. Individual semi-structured interviews offered the opportunity for each participant to share their story, and to make sense of their experience in a one-to-one research interaction. Rich, detailed first-person accounts of living with and beyond cancer were gathered and interpretations were developed using a dual hermeneutic process (the interpretive relationship between the researcher and participant, whereby the researcher attempts to make sense of the participant's account and the participant in turn makes sense of their own experience) (Smith et al., 2009).

Focus groups provided an opportunity for individual participants to share their experiences with other people who were also living with and beyond cancer. The group provided a space for participants to interactively understand each other's experiences, and to co-construct shared experiences. Our experiences of using focus groups to collect data in this study reinforces previous research by Munday (2006) in that focus groups were a suitable method for individuals to work together to form a collective identity as a group who share common values and ways of understanding themselves and their world (Munday J, 2006). For some,

the focus group provided an opportunity to meet others with similar experiences for the first time. This connection provided benefit beyond research by providing a sense of belonging in becoming a collective (*us cancer people*). Sharing experiences also extended to providing advice based on personal experiences of i.e., what had helped in certain situations, and support among participants was offered beyond the context of the research. The common experience of having received treatment for breast, prostate or colorectal cancer brought individuals together, participants were able to support each other to share their stories and manage the flow of the discussion with very little interaction from the researcher. The group interaction allowed for a depth of exploration, and provided rich, detailed individual and group-level accounts of living with and beyond cancer. The change in the balance of power in the researcher - researched relationship has important implications, both for the social context of the study, and for the findings that has opened up a new way of understanding living with and beyond cancer (Yardley, 2000). Interpretations were developed using a multiple hermeneutic process where the interpretive relationship whereby each participant makes sense of their own experience, the researcher makes sense of each participant's first-person account and of participants' attempts to make sense of each other's experiences (Montague, 2020).

The preliminary interview analysis allowed for identification of areas for further theoretical exploration, and informed focus group data collection. Focus groups were used to provide feedback on the preliminary analysis, to check the direction of researcher interpretation, and to clarify assumptions. In this way, focus groups provided access to lived experience, allowed participants to reflect on their own thoughts and feelings, to reflect on their own experiences with others, and to consider the experiences of others. In this way, the addition of focus groups expanded the research process by providing a stronger basis for creating nuanced understanding.

Study strengths and limitations

One strength of the study is the thorough and systematic application of interpretive phenomenological analysis. This commitment to methodological rigour provides depth and detail in our understanding of how living with and beyond cancer has been experienced (Yardley, 2000). Alongside, this study contributes to the understanding of what it means to live with and beyond cancer by complementing idiographic knowledge with multiple perspectives from a group of participants who are living with and beyond cancer. This preservation of diversity of IPA and the appreciation of inherent complexities of qualitative research complements more traditional methods and demonstrates the value of exploring multiperspectival IPA (Larkin, 2019). While some identify the complexity of multiple hermeneutics as a limitation, we highlight the benefit of moving around the hermeneutic circle to explore individual and group-generated accounts in order to add richness and robustness to IPA, and to make sense of living with and beyond cancer from the perspectives of all participants (Tomkins, 2010). However, it is important to note that the findings are specific to those selected from the open-access follow-up list and are not empirically generalisable. It is possible, however, to enhance transferability by describing the research context and assumptions, and by making connections between the analysis of participants accounts and claims in the extant literature (Elliott et al., 1999, Whitemore et al., 2001). Further research can also explore whether the meaning of living with and beyond cancer expressed by participants in our study holds true for other groups who are not on the open access pathway. While this study extends IPA methodology, one challenge has been the amount of time required for the cross-case analysis of the accounts of 44 people who are living with and beyond cancer, making the scope large for a qualitative study. The analysis process has been very time-consuming but critical to the quality of the study.

It is important to acknowledge the limitations of IPA. While IPA is attractive because of its applicability to understanding the meaning of living with and beyond cancer and its commitment to explore, describe, interpret, and situate the participants' sense making of their experiences, questions have been raised as to whether the approach accurately

encapsulates the experiences and meanings of experiences or whether it more likely captures opinions of experience (Tuffour I, 2017). A further critique of IPA relates to the complexity of defining phenomenology. With the study's IPA focus on how people make sense of their experience, it has been argued that this approach has more of a psychological and cognitive focus and is not consistent with a phenomenological perspective (van Manen M, 2017).

Future research

The NHS is committed to providing personalised care in order to improve the quality of life, self-management, and patient satisfaction for people who are living with and beyond cancer (England, 2019). Understanding patient experience is fundamental to improving healthcare, so future research will be grounded in co-design and participatory inquiry (Heron and Reason, 1997). Sophisticated methods like experience-based codesign (EBCD) can be used to involve people who are living with and beyond cancer, and clinical staff to explore how what we know about living with and beyond cancer can be used to inform the co-design and evaluation of a structured conversation tool that supports personalised care planning for long-term cancer care (Bate and Robert, 2006). EBCD is a collaborative approach that brings stakeholders together to provide opportunities for patient involvement in decision making about care planning and can provide the potential for transformational change (Robert et al., 2015). EBCD has previously been used successfully to develop complex interventions for supportive cancer care (Tsianakas et al., 2012b). The care of the growing number of people living with and beyond cancer needs to be tailored to better support people facing consequences of their diagnosis and treatment both in the short and longer term. Future research to investigate and co-design an approach to improve personalised care planning for people living with and beyond cancer in the longer term is proposed.

Conclusion

A call has been made to better understand the experiences of those who have completed primary cancer treatment (Foster and Fenlon, 2011, Fenlon et al., 2013) and to improve the long-term quality of life for people who live with and beyond cancer (Independent Cancer Taskforce, 2015). A key challenge for health services is the lack of clarity around what constitutes living with and beyond cancer. First-hand experiences contribute to the understanding of adjustment when faced with the adversity of living with and beyond cancer. This knowledge can be used to direct supportive cancer care and to ensure improved long-term quality of life for people who live with and beyond cancer. The novel multi-perspective IPA design presented in this paper allows us to move beyond the idiographic to a more comprehensive and detailed view of Living with and Beyond Cancer.

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Declarations of interest

None

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APPENDIX Supplementary File7

ODS1 Interview Schedule

ODS 2 Focus group topic guide

ODS 3 Interview participant characteristics

ODS 4 Focus group participant characteristics

ODS 5 Full coding framework

ODS 6 Living with and beyond cancer quotes across cancer type focus groups

ODS 7 Breast cancer quotes across interviews and focus groups