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Understanding the support needs of family members of people undergoing chemotherapy: A longitudinal qualitative study

Abstract

Purpose: Capture change in family members' experiences as they look after patients during chemotherapy, and understand variability in their needs for support.

Method: Longitudinal digitally-recorded qualitative semi-structured interviews with family carers at the beginning, mid-point, and end of treatment. Twenty-five family members (17 women, 8 men), mean age 52, were interviewed. Fifteen participants were supporting a relative having chemotherapy with curative intent, and 10 a patient receiving palliative chemotherapy. They were recruited from two UK locations: a regional cancer centre in Southampton and a comprehensive cancer centre in London. Sixty-three interviews were conducted in total, and the data were analysed using Framework Analysis.

Results: Three themes were generated from the data: *Changing lives, Changing roles*; *Confidence in caring*, and *Managing uncertainty.* These captured family carers' evolving needs and sense of confidence in caregiving during chemotherapy. Carers reported considerable anxiety at the outset of treatment which persisted throughout. Anxiety was underpinned by fears of disease recurrence or progression and concerns about treatment outcomes.

Conclusions: This study presents original fine-grained work that captures the changes over time in family carers' experiences of chemotherapy and their adaptation to caregiving. It provides fundamental evidence of the challenges that cancer carers face during patients' treatment; evidence that can be used as a basis for carer assessment and to build much-needed carer interventions. Oncology nurses should assess carers': ability to care; needs for information and support to prepare them for this; wellbeing over time; and, any support they may require to prevent them from becoming overburdened.

Keywords cancer; chemotherapy; family carers; longitudinal; qualitative; support needs

Highlights

Family members’ confidence in caregiving can grow as treatment progresses as long as they can access appropriate help when needed.

For carers of people having curative chemotherapy, anxiety and stress appear to accumulate over the treatment journey.

Carers’ experiences and needs should be assessed at multiple time points to enable healthcare professionals to respond effectively to their support needs.

1. Introduction

A cancer diagnosis profoundly affects both patients and their family and friends. In the United Kingdom, over 360,000 people are diagnosed with cancer annually (Cancer Research UK, 2018), and about 1.5 million people provide informal care for them (Macmillan Cancer Support, 2016). Informal carers - people including family and friends who give unpaid support to people with cancer - adopt a number of roles. During chemotherapy, these roles include being an advocate, companion, protector and practical caregiver (McIlfatrick et al., 2006; Ream et al., 2013). Further, carers provide patients with significant emotional and physical support, assist with symptom management, help administer medicines and coordinate care (Ullgren et al., 2018).

Supporting someone through cancer comes at a cost. Carers can experience extreme strain, anxiety and distress (Grimm et al., 2000; Aranda & Hayman-White, 2001; Matthews, et al., 2003; Deshields et al., 2012; Lambert et al., 2016). This is particularly pronounced during chemotherapy (Renovanz et al., 2018), a treatment associated with toxicities that can prove life-threatening at worst (NCEPOD, 2008) and impact quality of life at best. It evokes considerable fear (Bell, 2009; Hofman et al., 2004) in patients and carers and their anxiety is compounded by chemotherapy typically being provided in outpatient settings. This requires them to monitor and manage side-effects at home (McIlfatrick et al., 2006; McKenzie et al., 2017; Ullgren et al., 2018).

Carers report that their needs for information and support are often overlooked by healthcare professionals (Ussher et al., 2009) and consequently go unmet (Sklenarova et al., 2015). They report low self-efficacy in providing care , insecurity around both managing chemotherapy side-effects and recognising changes in patients' health (Williams et al., 2013) and concerns over ensuring patients' safety during chemotherapy (Applebaum and Breitbart, 2013).

Through developing a fine-grained understanding of carers' needs for support during cancer treatment, healthcare professionals can develop, evaluate and implement pertinent interventions to alleviate carer distress and enhance their caregiving capacity. While a number of studies have reported on carers' support needs during chemotherapy (McIlfatrick et al., 2006; Ream et al., 2013; Norton et al., 2019), few have examined these over time; a perspective that would give insight into how carers' support needs and confidence in caregiving change as treatment unfolds. Some studies have used a longitudinal approach when exploring cancer carers' experience more generally (Murray et al., 2010; Girgis et al., 2013; Walshe et al., 2017; Roberts et al., 2018) but the challenges faced by carers during chemotherapy have not featured. Few interventions have been developed to address carer needs during chemotherapy (Tsianakas et al., 2015).

We sought to address the evidence gap by undertaking a longitudinal qualitative study to describe carers' experiences whilst supporting relatives through chemotherapy and to explore how their support needs and caregiving confidence evolved during of treatment. We focused on the needs of family members as they predominantly – over friends – provide this support. We purposively sampled family members of people having either curative or palliative treatments in order to gain understanding of how this context may impact experience. Such inquiry has not been undertaken to date.

2. Methods

2.1. *Design*

A longitudinal qualitative design was adopted, entailing digitally-recorded semi-structured interviews conducted with family carers at three points during patients' treatment with intravenous chemotherapy: start of treatment (T1), mid-point (T2) i.e. point where half of the planned cycles of chemotherapy had been administered, and completion of chemotherapy (T3). Interviews focused on carers' need for information and support from healthcare professionals and factors that affect their confidence and competence in caring for someone over the course of chemotherapy. Analysis of longitudinal data can provide rich understandings of changes and/or stability over time, factors that may account for these, and both how and why experiences may vary between individuals (Saldaña, 2003; Calman et al., 2013).

2.2. *Participants*

We specifically sought carers of people having combination chemotherapy treatments incorporating cisplatin; these treatments produce significant toxicity and, it was envisaged, would give insight into how carers would manage difficult side-effects. Carers were identified by patients and recruited from a comprehensive cancer centre in London and a regional cancer centre in Southampton, in the south of England, between April 2011 and May 2012. Patients new to chemotherapy were screened for eligibility by the clinical team and approached for consent to recruit the family member they considered their principal provider of care. Patients were usually approached when they attended a pre-treatment consultation. Eligible patients were: receiving cisplatin-based chemotherapy for gynaecological, lung, testicular or colorectal cancer; over 18 years; willing for their family member to be approached; able to communicate in English; having first ever course of chemotherapy; and without any cognitive impediment. Eligible carers were: family members nominated by patients as providing most support; over 18 years; able to communicate in English; and able to comply with the research protocol.

Twenty-five participants were sought. This sample size reflects recommendations that qualitative researchers interview fewer than 50 interviewees (Ritchie and Lewis, 2003) in order to maintain quality of data collection and allow in-depth analysis. Further, it is suggested that limited new information is revealed when more than 25-30 participants are interviewed (Hennink et al., 2017). In this study, the research teams in Southampton and London reviewed collectively the data every two weeks to establish the point at which no new information was being generated - information that would either enhance or alter the study findings – indicating that data saturation had been achieved and data collection could cease. Data saturation was achieved at each time point despite fewer interviews being conducted over time (see findings).

To capture a broad range of experiences relating to caring for a family member through chemotherapy, carers were selected purposively according to: treatment intent (curative/palliative); age (younger /older than retirement age); gender and, relationship to the patient (spouse/partner and other relationships).

2.3. *Qualitative interviews*

The study was approved by the North London REC3 (now London-Harrow NHS Ethics Committee) REC Ref: 11/H0709/2. The first interview (T1) asked about: perceptions and expectations of chemotherapy; changes to everyday life that had been introduced; information and support needed; and that provided by healthcare professionals. The second (T2) focused on: status of work and other commitments since previous interview; symptoms, side-effects and unplanned for events (e.g. hospitalisation) experienced by their relative; help-seeking undertaken; experience of caring; feelings of confidence and competence in caring; needs for information and support and level to which they were met. The final interview (T3) was similar to T2 except it additionally discussed carers’ experiences of chemotherapy in relation to their expectations at the start.

Interviews were undertaken by two researchers (JF-J and RF), varied in length from 11 minutes to 1.5 hours, were recorded digitally and were professionally transcribed. They were undertaken in a venue of carers’ choice: 18 were undertaken in carers’ private homes; 19, over the telephone; 23, within the hospital setting, and 3, at the carers' workplace.

2.4. *Data analysis*

Interview data were analysed using Framework Analysis (Ritchie & Lewis, 2003), a matrix-based approach for collating, reviewing and understanding qualitative data- suitable for analysing longitudinal data (Ritchie & Lewis, 2003). A thematic coding framework was devised from recurrent themes within the data (RF, JFJ, ER) and applied across transcribed accounts (RF, JFJ). Coded data were transferred to a matrix that allowed data from each of the interviewees' three interviews to be integrated (rather than analysing each set of interviews independently). Matrices incorporated both narrative summary and relevant quotes in accordance with the Framework Analysis approach (see Figure 1a).

[insert Figure 1 here]

The data were analysed both cross-sectionally through construction of matrices (Figure 1a), and longitudinally (Calman et al., 2013) through mapping individuals' data over the three time periods (Figure 1b). These processes enabled identification of both convergent and divergent experiences between carers at each time point and the capture of within- individual dynamics. It was possible to identify changes in experiences and perceptions over time, both within and across individuals, to explore how these arose and to posit some explanations for them. Data analysis commenced as data were generated and was iterative; the researchers moved back and forth in a systematic manner between generating interview data and analysing them thus allowing areas of questioning to develop as understanding of an area grew or additional clarity was sought.

3. Findings

One hundred and one patients were screened for eligibility and 64 eligible carers were approached about the study in order to consent 25 carers as planned. Five carers withdrew before the second interview, and a further two before the third. Withdrawals followed deterioration in patients' health or their death (see Figure 2).

[insert Figure 2 here]

Seventeen female and 8 male carers were recruited, their average age was 53 years; most were a spouse/partner (n=19). Fifteen carers were supporting a patient having curative chemotherapy (marked 'C' before the participant's number). The remainder supported patients having palliative chemotherapy (marked 'P') (see Tables 1 and 2 for participants' details).

[insert Tables 1 and 2 here]

Data analysis identified three themes that which reflected carers' experiences and support needs over time: *Changing lives, Changing roles*; *Confidence in caring*, and *Managing uncertainty*. These themes endured over time but some aspects of them – sub-themes – varied as treatment progressed and patients' needs altered. Some appeared linear with trends (either improvement or decline) over time, whilst others had no evident pattern. Some differences in carer experience were evident according to the intent of patients' treatment (curative versus palliative) (see Table 3).

[insert Table 3 here]

3.1. Changing lives, changing roles

The first theme indicates how, across time, carers' lives changed as did the roles they undertook in supporting patients. Carers found that they rapidly (from T1) had to undertake more roles within the home as many relatives' felt the immediate effects of treatment. These obligations grew with time (T2 and 3) and many carers felt accompanying stress. The changing domestic dynamic appeared to have a knock-on effect that was felt more keenly over time (by T2 and T3) on relationships with some becoming stronger and others frayed. Concerns over financial stability were constant (present from T1 and persisting to T3) and influenced by working carers' decisions to decrease (due to caregiving requirements) or increase (due to financial need) employment as needed. A balance was evident for those of working age – between caregiving and working - that was challenging for some to achieve.

3.1.1. You doing everything

At the start of treatment, carers described how their lives had been disrupted by the patient's cancer diagnosis and the many new roles that they undertook in caring for their relative. They were willing to provide care and wanted to help, but the impact was immediate:

> *Well, every day after work I have to come over here or I meet my mum and we go to treatment. Or whatever days I'm off I'm over here, cleaning the house, cooking and washing clothes and make everything sterile and make sure everything's clean so that she doesn't get an infection… I live on my own so it's like living two lives*. (C4, F, 28, daughter)

By the second interview, a pronounced sense of chemotherapy taking over carers' lives was evident as caregiving roles began outstripping other social roles and caregiving became 'a job in itself'. Carers not used to housework, or caring in a physical capacity, felt an acute sense of strain. Some carers of people having curative treatment struggled with the ongoing burden of caregiving and voiced some growing frustration and resentment:

> *Yeah still doing it all but resentments kicked in. I don't know if I said that last time, I think it's just a recent thing. Because when he was in hospital I kept going because you do. But when he's home and he's just laid there, you doing everything, you're tidying up, you're doing the kitchen, you cutting the grass and he's just sat there and you think you know he can't, but at the same time you [think], lazy git.* (C5, F, 44, partner)

It was clear that the stress felt by carers, created by caregiving during chemotherapy, did not abate with time. A high level of unremitting stress, that commenced when chemotherapy started, was felt by all carers. The burden of helping to manage patients' treatment and the associated disruption to carers' lives appeared to increase with time.

3.1.2. Impact on our interactions

Carers accounts made it evident that relationships between carers and patients often changed over the course of chemotherapy; for some relationships improved, whilst for others they declined. By treatment mid-point, carers' everyday roles had changed – many had to undertake additional household chores and were instrumental in ensuring patients attended appointments, took medications and attained help from clinical teams if they become unwell. While for some patient-carer dyads, this changed dynamic within relationships and the home helped to make bonds between them stronger, others found relationships became strained:

> *It would be easy for me to feel that she doesn't always appreciate what I do for her but there again you can't expect people to be continually grateful for what you're doing… Just occasionally, erm, she'll be feeling so fed up that, erm… that does impact on our interactions*. (P10, 78, M, husband)

The impact of treatment on personal connections extended to broader relationships. Some carers felt distanced from family members and friends and unable to engage in everyday social roles through needing to be at home. They described feeling 'isolated' and struggling to commit to arrangements (P5, 35, M, fiancé). In contrast, other carers, particularly those caring for a relative having palliative chemotherapy, reported feeling closer to, and very supported by, other members of their family. One man caring for his wife with mesothelioma described how his bond with his sons had strengthened:

> *My two boys now, we now go out every two or three weeks on a Saturday. We have lunch and then we have a few beers, which we never used to and I think this is all because they are*

> *looking out for me. […] We never used to do it on a regular basis it's about time we did, life's too short, as I said, and now we do that.* (P7, M, 68, husband)

Thus, although there was a trend over time for carers' relationships to be altered, these could become either fractured or enhanced during chemotherapy according to individual circumstance. Further, this could apply to relationships with not only with the patient but also with their wider family, friendships and social groups.

3.1.3. I'm the breadwinner

Thirteen carers were in employment at some point during data collection. At first interview, they reported challenges with balancing demands of caring with those of work:

> *I'm the breadwinner at the moment and I need to keep that going so it is difficult. Mentally, I can cope when I haven't got to do the work-side and just concentrate on him and the house*. (C5, F, 44, partner)

Concerns over financial stability were clear from the outset for most carers. Their anxieties were compounded or lessened according to employers' attitudes and practices. Some carers reported having flexible and understanding employers who allowed them time off to support patients at appointments or though periods of acute illness. However, others had inflexible employers; it was not uncommon for them to take unpaid leave or holiday to cover caregiving responsibilities, making their support of patients harder to manage.

Carers' concerns over remaining in employment, and earning sufficiently to support their needs, were unabating over the course of their relatives' treatment. Indeed, by the third interview, the need to work reduced the level of support some carers could offer patients, e.g. some needed other family members or friends to attend patients' treatment in their place. Carers' work commitments were often driven by reduced financial circumstances due to patients' inability to work.

3.2. Confidence in caring

The second theme reflects carers' confidence in supporting their relative through chemotherapy and managing the side-effects associated with it. Three sub-themes were evident that showed how carers collectively progressed from: trepidation over side-effects and uncertainty about when and how to seek help for them (T1); to growing confidence in recognising and addressing important side-effects (T2); to, the caregiving process becoming routine or second-nature (T3).

3.2.1. We weren't sure if it was a problem

During the first interview, carers expressed trepidation over monitoring chemotherapy side-effects. Some felt well-prepared – buoyed by the assumption that they would have easy access to healthcare professionals to convey 'look, this is happening, or, I can't do this, or so on and so forth. Help!' (P7, 68, M, husband). In practice, this contact and reassurance was not always forthcoming. One carer explained how she could not access help over the weekend, while others found it challenging to decide what constituted an 'urgent' concern:

> *…you can page a registrar if it's urgent but we weren't sure if it was a problem or if it was urgent, so that was probably the most stressful thing, not knowing whether you should phone them in the middle of… it was only like 11pm but whether just to… so we just waited until the morning*. (C11, 27, F, girlfriend)

3.2.2. You know what to look out for

By treatment mid-point, carers felt more confident in recognizing severe symptoms and had a better understanding of when help-seeking for them was warranted:

> *I think as it's gone on, you just know what to look out for and you kind of get a feel for what's a problem and what isn't too much of an issue, and just getting used to it, I think*. (C11, 27, F, girlfriend)

However, as at T1, they believed it essential to have direct access to healthcare professionals when required in order to continue building and maintaining confidence in caregiving. Carers felt more confident in caregiving when they received prompt help from healthcare professionals, and when they trusted their acute oncology service. Where help-seeking had proved difficult early in the treatment trajectory, carers remained concerned over monitoring and managing acute treatment toxicities.

3.2.3. Doing it all the time

By the end of treatment, most carers reported feeling confident in their ability to support their relative through chemotherapy and its associated side-effects. This reflected their familiarity through 'doing it [caregiving] all the time'. However, when new - or less tangible - symptoms arose e.g. fatigue or weakness, carers reported feeling unsure of how best to help. This undermined some carers' confidence in their ability to resolve issues and concerns. They also perceived that their confidence in caregiving was enhanced through establishing trusting relationships with healthcare professionals:

> *I got more confident because I knew what I was doing, I knew where I was going. The people were recognisable, they all recognised [patient] and, you know, if I had any problems I felt that they were friendly enough and easy approachable, not sort of someone that I would find intimidating or anything. I could just go up to them and sort of say… no matter if it was a little thing that, you know, oh we've been feeling like this, is this normal?* (C8, 51, F, mother)

Whilst time and experience increased carers' confidence in managing side-effects and in gaining help when it was needed, some carers retained elements of uncertainty and felt strong need for ongoing guidance from healthcare professionals.

3.3. Managing uncertainty

This theme reflects the manner in which carers experienced uncertainty across the course of patients' chemotherapy with them expressing trepidation at first (T1) and associated anxiety. Thereafter, they referred to the benefits of routine as they adjusted to the 'new normal' of living through chemotherapy and of feeling more in control (T2). Towards the end of treatment (T3) carers were reflective and voiced new concerns, renewed anxiety and increased trepidation as treatment ended. There appeared some differences according to whether patients' treatment was either curative or palliative.

3.3.1. Steel myself for anything

As treatment started, carers voiced concerns about the future, notably about treatment side-effects that they were anticipating. For carers of people having curative chemotherapy, uncertainties became more pronounced as the reality of treatment set in and anxieties manifested about how their relatives would manage:

> *Well I thought to myself well I'd better steel myself for anything here because I don't know how it's going to affect her every day, and I was getting a bit concerned about whether she would be able to, would she be in a state to be at home on her own if I was working*. (C3, M, 63, husband).

For some, concerns over disease recurrence appeared at the root of their anxieties; they were concerned that their relative would undergo unpleasant side-effects and risks of chemotherapy without attaining the intended remission from disease. Three carers of people having curative chemotherapy reported physical complaints at T1 which they related to stress.

Carers of people having palliative chemotherapy expressed less anxiety at the start of treatment, as they '*just had to deal with it*' (P8, F, 33, daughter). They articulated acceptance and viewed treatment as offering hope whilst acknowledging that death might be inevitable. Carers' desire for information about prognosis varied: information helped some manage uncertainty – they wanted to know '*what to expect*' (P7, M, 68, husband), whilst others felt strongly that they did not want to know more. One explained '*when we saw the oncology specialist at X hospital well she went into so much detail, and we thought why do we need all this detail, you know*' (C12, M, 78, husband).

3.3.2. Taking control

By treatment mid-point, carers voiced how routines of treatment – and the familiarity of associated symptom patterns – reduced uncertainty. Although caregiving and the demands of patients' treatment remained unremitting, knowledge of what was happening provided a sense of control:

> *I know what the routine is and I expect him to be slightly more poorly in his full week than the week that he is doing one day. So I think, you come to terms with it... I mean, it's become like a routine now. I know what's expected. I know it's going to take 5 hours and I try to manage my time… it's become a bit more… not easier, but it's become a bit more routine because I know what to do now*. (C8, 51, F, mother)

However, this was not the same for everyone – for some, the side-effect patterns (with marked peaks and troughs) stimulated pre-emptive worry over future cycles of treatments and potential difficulties.

Many carers of people having palliative treatment reported that side-effects were fewer than anticipated and they talked positively (as they had at T1) about the ‘glimmer of hope’ (P8, 33, F, daughter), sense of ‘momentum’ and ‘taking control’ that treatment provided (P3, 54, F, daughter). However, for some, fears about how they would manage if the patients’ health declined had turned to ‘dark moments’ and ‘anger’ (P7, M, 68, husband).

In contrast, carers of people having curative treatment voiced a sense of the journey peaking, with side-effects taking longer to subside and their own energy running low. These carers reflected on a new normality shaped by cancer and its treatment, and their reflections were tinged with anxiety when they (often erroneously) interpreted side-effects as signs of cancer spreading.

3.3.3. How do we get to the other side?

The final interview provided a chance for carers to reflect. For carers of people having palliative chemotherapy, there was a sense that chemotherapy had been ‘a lot less scary’ than initially feared (P8, F, 33, daughter). However, the end of treatment also heralded feelings of anxiety for them; concerns remained over how patients could deteriorate and how they would cope as end of life neared. For carers of people having curative chemotherapy, anxiety and stress appeared cumulative. Carers spoke of the need to transition to ‘the other side’ of treatment as they contemplated what might happen next:

> … *now everything’s over it’s actually, oh my god, we’ve just done all that and we’ve survived [to] the other side, because before we started I said to [patient] how do we get to the other side when we get there?*’ (C5, 44, F, partner)

As one carer articulated, her worries were ‘always going to be there’ in the future as monitoring and check-ups continued (C8, F, 51, mother). After the routine of treatment and structure of appointments, there emerged a return to uncertainty – as one participant explained, there was an acute sense of uncertainty over 'what does the future hold?' (P8, 33, F, daughter).

4. Discussion

This is a first study of its kind to describe the experiences over time of carers supporting family members through chemotherapy, and to detail how their needs for support and their confidence in providing care change over the course of treatment. Further, it allowed comparison between the experiences of carers according to whether their relatives were being administered curative or palliative treatment. The study's longitudinal qualitative design captured the changes over time in carers' experiences and identified how they could vary according to patients' disease status, treatment intent and individual circumstance.

Across the sample, there was a sense that carers – whilst willing to support their relatives through chemotherapy – sometimes felt overwhelmed by the burden of patients' illness and its associated treatment. Past research has established that treatment itself is burdensome and can disrupt patients' daily lives, decrease their desire to follow onerous and complex treatment schedules and diminish patients' overall quality of life (May et al., 2009). We argue that these burdens are experienced as much by carers as patients. Indeed, previous literature suggests that cancer carers can be profoundly affected during patients' chemotherapy (Grunfeld et al., 2006; Jenewein et al., 2008). Carers report that the changes to everyday lives, required to support someone through chemotherapy, are challenging to adapt to (McIlfatrick et al., 2006; McKenzie et al., 2017; Schmer et al., 2008). This study identified that carers in employment – particularly those struggling to meet work commitments – are particularly vulnerable to burden and distress. Given that around 50% of carers are in employment (Kent et al., 2019), there is a sizeable population whose vulnerability and needs during patients' chemotherapy need to be assessed and addressed. Further, this study ascertained that many work-related stressors arise at the start of treatment suggesting that healthcare professionals need to be proactive at this time, as well as revisiting issues related to work later on.

The importance to carers of having easy and quick access to health professionals to consult if their relative becomes unwell was evident in this study. However, rapid and straightforward access was not experienced by all carers. This was particularly problematic if lack of support was encountered early in treatment - when carers had uncertainties over what to expect or how to go about help-seeking. Challenges with consulting with professionals will arguably contribute to the isolation, fear and low confidence in caregiving that some carers report (Ream et al., 2013). Further these feelings are liable to increase any anxiety and depression; levels of anxiety in carers can be higher than those experienced by patients and endure for at least five years following patients' diagnosis (Girgis et al., 2013).

This study, one of only a few to investigate carers' experience and needs over time, found that their contributions to carers' roles and contributions (McIlfatrick et al., 2006) in a somewhat static fashion, failing to highlight the dynamic nature of their caregiving contribution. Further, this study depicted how carers' confidence in caregiving grew as treatment progressed as long as they could access appropriate help when needed. With the advent of acute oncology services, the challenge for patients and carers of gaining quick access to oncology professionals when needed has largely lessened (Neville-Webbe et al., 2013).

It was also noteworthy how the outlook and perceptions of chemotherapy held by our study participants – as either a treatment to be feared or one offering hope – differed according to whether chemotherapy was being given to prevent recurrence or as a palliative measure. Additionally, carers' views on transition to life post-chemotherapy varied markedly although all were characterised by uncertainty, at marked odds to feelings of control generated by the routine of treatment. For carers of people having curative treatment, fear of recurrence was evident. For those caring for people completing palliative treatment, uncertainties predominantly centred around the length of time before disease would progress and their – and patients' – likely resilience as end of life neared. The literature increasingly refers to patients' fear of recurrence and this concept is relatively well-researched (Armes et al., 2009); however, the nature of fear of recurrence and/or progression held by carers is much less researched, with few exceptions (Hodges & Humphris, 2009).

Our research suggests that it is important for healthcare professionals to: i) appreciate differing perspectives held by carers towards chemotherapy according to patients' prognosis and treatment intent; ii) understand how carers' ability to provide care and associated burdens of caring are affected by both patient need and their own capacity to care; iii) recognise the challenge for carers on transition to life following chemotherapy, and iv) develop and institute appropriate supportive interventions for carers that can accommodate their changing experience and need.

It is important to note that our research focused solely on people that had carers; not every person with cancer has a family member or friend to look after, and support, them through chemotherapy. It is important that the experiences of people without carers to call upon are understood as these patients are likely to find the rigours and burdens of treatment harder to contend with than their counterparts with carers. Interestingly, this group has been the subject of little research to date.

4.1 Strengths and limitations of the study

One strength of this study lies in its longitudinal qualitative design which enabled carers' experiences to be captured along the treatment trajectory, advancing much needed conceptualisation of their experiences (Fletcher et al., 2012) and their adjustment to their role. Whilst a few other studies (e.g. Taylor et al., 2016) have taken a longitudinal qualitative approach to explore carers' experiences during patients' treatment for cancer, they have not specifically focused on how carers' experiences vary during chemotherapy – a particularly challenging form of treatment that can pose high risk to patients.

The main limitation to the study lies in the fact that the findings represent only some carers' experiences. From 64 eligible carers approached about the study, around 60% (of either patients or their carers) declined participation as they felt that they had too much to deal with without taking part. Arguably, the carers and patients who declined participation may have had more acute needs and/or more diverse experiences than the ones who participated.

Additionally, it was not possible to comment on the experience over time of those who withdrew between the first and last interview. These carers withdrew because either their relatives' health had declined or they had died.

The majority of those interviewed were the patients' partner or spouse. However, these carers intimated during their interviews, that wider family members were affected by their relatives' chemotherapy and were also involved in – and affected by - caregiving. These carers were not represented within our sample. The complexity of situations involving multiple carers warrants further investigation.

Another potential limitation to the study relates to the fact that we recruited only carers of people being treated with cisplatin-based treatments; treatments known to have significant toxicity. It is possible that carers looking after patients receiving different chemotherapy treatments may have had different experiences from those captured in this study.

5. Conclusions

Chemotherapy is – and will remain – an important treatment for cancer for the foreseeable future and will continue to be delivered primarily in day care settings. This requires carers to take considerable responsibility for patient wellbeing at home. Carers play an important role in patient safety – recognising and responding to symptoms and knowing when to access help for acute toxicities which can lead to sudden patient deterioration. It is essential that healthcare professionals prepare carers and ensure that they are well equipped for, and supported in, caregiving in; this will help to safeguard patient safety. Carers' input enables healthcare services to operate and contributes substantially to cost reduction at the end of life (Round et al., 2015) as patients and clinicians rely on carers' support and care management skills (McKenzie et al., 2017). This study suggests that some carers are at risk of becoming overburdened by requirements imposed by patients' illness, fear for the future and requirements of treatment. However, conversely carers can be very positive, upbeat and manage caring without detriment to their own wellbeing. Thus, it is important that they have their caring ability and needs assessed, particularly as they may be reluctant to ask for support (Renovanz et al., 2018). The demands on them – and their needs for assistance – are often overlooked (Ussher et al., 2009). Given the dynamic nature of carers' experiences, this study suggests that their needs should be assessed periodically.

Finally, as indicated in previous research focusing on cancer carers' needs (Ream et al., 2013), this study points to the need for carer interventions that prepare carers for, and sustain them during, caregiving. Such interventions need to be pragmatic and feasible to deliver in what is effectively a clinical busy setting. One intervention – Take Care® – reported in the literature outlines the potential of a brief educative intervention for enhancing carers' self-efficacy for caregiving during chemotherapy (Tsianakas et al., 2015). It is the only intervention written about in the literature developed specifically for supporting cancer carers during this time. This is clearly an area that needs greater research and development in future.

Conflicts of interest

None declared.

Ethical approval

This study was approved by North London REC3, REC reference number 11/H0709/2.

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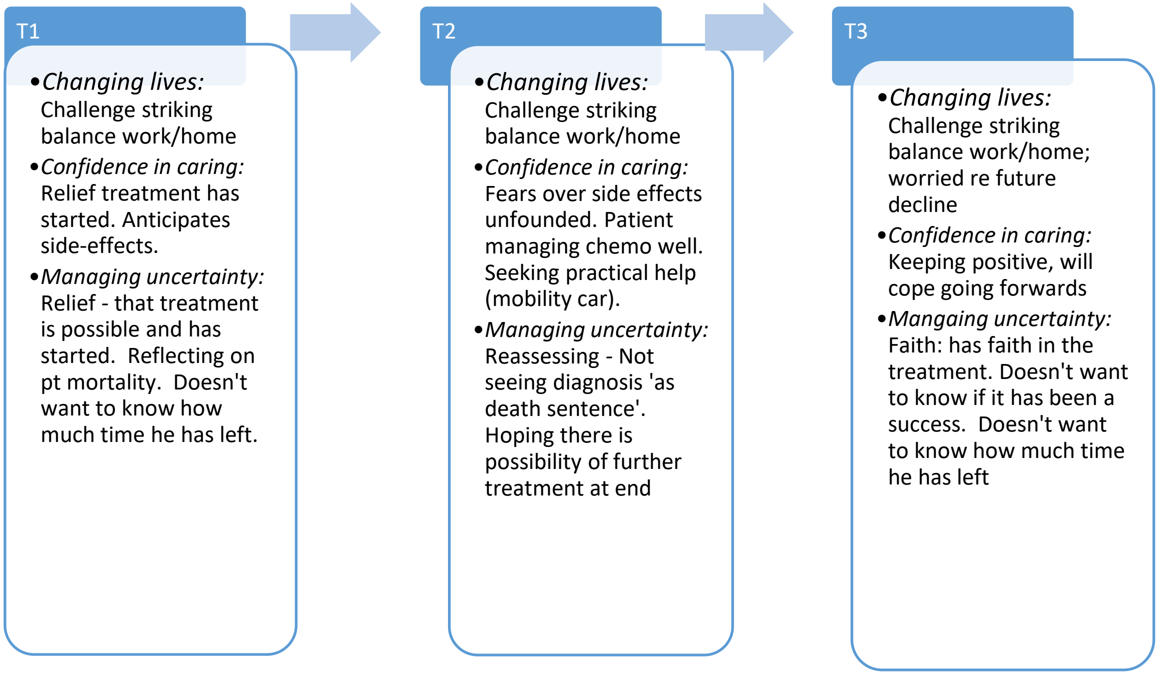
Figure 1. Extracts depicting data analysis process

1a: Example of matrix used in longitudinal analysis: Combining working and caring responsibilities

ID	Carer gender Treatment intent	Relationship with patient	Combining working and caring responsibilities
C3	F Curative	Husband	**T1**: Finding it very tiring combining work and caring responsibilities **T2**: Difficulties juggling both. '… there were times when she [his wife] was so bad that I had to ring up work and say I can't come in I've got to help, you know…'. Work have been very accommodating. **T3**: No data – no interview possible
C6	M Curative	Wife	**T1**: Has had to use annual leave to accompany husband to hospital. Only two days paid leave left. **T2**: Still working, employers really supportive allowing her to take time off as required. Annual leave nearly run out. **T3**: Continuing working. Taking unpaid leave as needed.
C11	M Curative	Girlfriend	**T1**: Not working. Appears overwhelmed emotionally, exhausted. Recognises if did work she's unsure how she would accommodate chores, caring responsibilities as well as job **T2**: Mentions she is a procrastinator. Wants to look for work, but finding it hard to get motivated to do this. **T3**: Back in work but: 'it's been really hard doing both at once and I do kind of feel it must be what Mums feel like when they go back to work, like I'm not doing really either of them properly - but erm, I think I'm seeing it as a short-term thing and the hoping if you know all is well with his scan results…I'd rather work at the moment while he is able to get up and about and do things for himself'.
P1	M Palliative	Wife	**T1:** Working: using free periods (is supply teacher), when she doesn't need to be at school, to be with her husband. Has two lodgers who she now has to cook for (husband was responsible for household tasks). They have livestock that need taking care of. **T2:** Livestock have been moved closer to home so that she can keep an eye on them more easily. **T3**: Trying to ensure hospital appointments are scheduled so that she doesn't have to take time off work. But if she needs to, she will.
P8	M Palliative	Daughter	**T1**: Not working **T2**: Stresses her father is her priority, but struggling without regular income, looking for flexible freelance jobs. Finds it difficult not being able to afford simple things to cheer herself up. Everything a 'juggling act' especially as she also has chronic illness herself. **T3**: Now working so unable to accompany her father to treatment, boyfriend is helping out… 'the big factor now is there's not anyone that's really replaced my time with Dad, so you know, it's quite snatched time I'm spending with him now. With his last chemo my boyfriend rearranged his job and went to Dad's chemo with him'.

1b: Example of mapping over time for Carer P1



T1

- *Changing lives:* Challenge striking balance work/home
- *Confidence in caring:* Relief treatment has started. Anticipates side-effects.
- *Managing uncertainty:* Relief - that treatment is possible and has started. Reflecting on pt mortality. Doesn't want to know how much time he has left.

T2

- *Changing lives:* Challenge striking balance work/home
- *Confidence in caring:* Fears over side effects unfounded. Patient managing chemo well. Seeking practical help (mobility car).
- *Managing uncertainty:* Reassessing - Not seeing diagnosis 'as death sentence'. Hoping there is possibility of further treatment at end

T3

- *Changing lives:* Challenge striking balance work/home; worried re future decline
- *Confidence in caring:* Keeping positive, will cope going forwards
- *Mangaging uncertainty:* Faith: has faith in the treatment. Doesn't want to know if it has been a success. Doesn't want to know how much time he has left

Figure 2: Flow of participants through the study

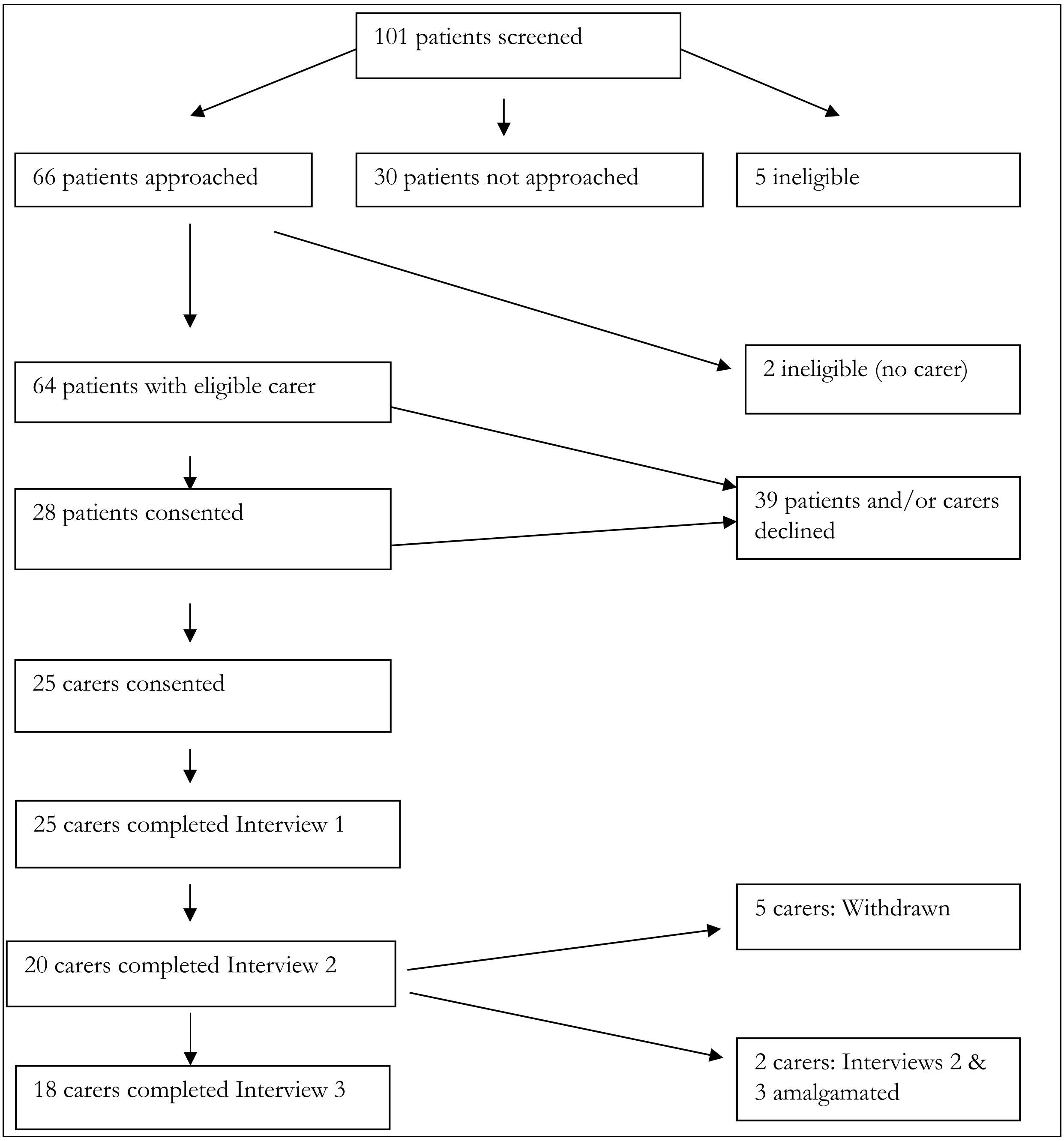


Table 1. Characteristics of carers recruited to the study

Age	Mean 52.6 (range 18-78)	
	N	%
Gender		
Female	17	68
Male	8	32
Relationship to patient		
Spouse/partner	19	76
Daughter	5	20
Mother	1	4
Patients' cancer diagnosis		
Lung	11	44
Colorectal	6	24
Cervical	3	12
Testicular	2	8
Ovarian	2	8
Endometrial	1	4
Intent of treatment		
Curative	15	60
Palliative	10	40
Length of treatment		
>4 months	10	40
2-4 months	9	36
<2 months	6	24

Table 2. Details of the individual carers

Carer ID	Carer age	Carer gender	Relationship to patient	Patient's diagnosis	Intent of treatment	Length of treatment
P1	51	Female	Wife	Lung	Palliative	>2-4 months
P2	35	Female	Wife	Lung	Palliative	>2-4 months
P3	54	Female	Daughter	Lung	Palliative	>2-4 months
P4	65	Female	Wife	Lung	Palliative	>2-4 months
P5	35	Male	Fiancé	Colorectal	Palliative	>2-4 months
P6	60	Female	Wife	Colorectal	Palliative	>4 months
P7	68	Male	Husband	Mesothelioma	Palliative	>4 months
P8	33	Female	Daughter	Mesothelioma	Palliative	>4 months
P9	67	Female	Wife	Lung	Palliative	<2 months
P10	78	Male	Husband	Ovarian	Palliative	>2-4 months
C1	75	Male	Husband	Lung	Curative	<2 months
C2	60	Female	Wife	Lung	Curative	>4 months
C3	63	Male	Husband	Colorectal	Curative	>2-4 months
C4	28	Female	Daughter	Cervical	Curative	<2 months
C5	44	Female	Partner	Lung	Curative	<2 months
C6	29	Female	Wife	Testicular	Curative	>2-4 months
C7	65	Female	Wife	Colorectal	Curative	>4 months
C8	51	Female	Mother	Testicular	Curative	>2-4 months
C9	25	Female	Daughter	Lung	Curative	<2 months
C10	71	Male	Husband	Cervical	Curative	>4 months
C11	27	Female	Girlfriend	Colorectal	Curative	>4 months
C12	78	Male	Husband	Ovarian	Curative	>4 months
C13	66	Female	Wife	Colorectal	Curative	>4 months
C14	70	Male	Husband	Endometrial	Curative	>4 months
C15	18	Female	Daughter	Cervical	Curative	<2 months

Table 3. Change in carers' needs and experiences over time

	Constant	**Fluctuating; no evident pattern**	**Increasing with time**
Theme 1: Changing lives, Changing roles			
Changed role at home, burden of responsibility *(Subtheme: You do everything)*			*
Stress & worry over maintaining work and/or duties in the home & caring responsibility *(Subtheme: You do everything)*	*		
Impact on relationships; either strengthened or strained *(Subtheme: Impact on interactions)*			*
Financial worries *(Subtheme: I'm the breadwinner)*	*		
Theme 2: Confidence in Caring			
Need for health care professional input, support & information *(Subtheme: We weren't sure it was a problem)*	*		
Confidence in accessing help & identifying problems *(Subtheme: You know what to look out for; Doing it all the time)*			*
Challenges with new symptoms and situations *(Subtheme: We weren't sure it was a problem)*		*	
Theme 3: Managing Uncertainty			
Fear about recurrence or spread (Curative patients) *(Subtheme: Steel myself for anything)*	*		
Worries about patient's decline and end of life (Palliative patients) *(Subtheme: How do we get to the other side?)*			*
Belief that treatment offers hope (Palliative patients) *(Subtheme: Steel myself for anything)*	*		
Needs for information (*Subthemes: Steel myself for anything; Taking control)*	*		
Anxiety and stress *(Subthemes: Steel myself for anything; How do we get to the other side?)*		*	