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

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**14 Abstract**

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

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

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

29 *Conclusions:* This study presents original fine-grained work that captures the changes over time in  
30 family carers' experiences of chemotherapy and their adaptation to caregiving. It provides  
31 fundamental evidence of the challenges that cancer carers face during patients' treatment; evidence  
32 that can be used as a basis for carer assessment and to build much-needed carer interventions.

33 Oncology nurses should assess carers': ability to care; needs for information and support to prepare  
34 them for this; wellbeing over time; and, any support they may require to prevent them from  
35 becoming overburdened.

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

37

**38 Highlights**

39

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

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

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

## 46 1. Introduction

47 A cancer diagnosis profoundly affects both patients and their family and friends. In the  
48 United Kingdom, over 360,000 people are diagnosed with cancer annually (Cancer Research UK,  
49 2018), and about 1.5 million people provide informal care for them (Macmillan Cancer Support,  
50 2016). Informal carers - people including family and friends who give unpaid support to people with  
51 cancer - adopt a number of roles. During chemotherapy, these roles include being an advocate,  
52 companion, protector and practical caregiver (McIlfatrick et al., 2006; Ream et al., 2013). Further,  
53 carers provide patients with significant emotional and physical support, assist with symptom  
54 management, help administer medicines and coordinate care (Ullgren et al., 2018).

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

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

68 Through developing a fine-grained understanding of carers' needs for support during cancer  
69 treatment, healthcare professionals can develop, evaluate and implement pertinent interventions to  
70 alleviate carer distress and enhance their caregiving capacity. While a number of studies have

71 reported on carers' support needs during chemotherapy (McIlfatrick et al., 2006; Ream et al., 2013;  
72 Norton et al., 2019), few have examined these over time; a perspective that would give insight into  
73 how carers' support needs and confidence in caregiving change as treatment unfolds. Some studies  
74 have used a longitudinal approach when exploring cancer carers' experience more generally  
75 (Murray et al., 2010; Girgis et al., 2013; Walshe et al., 2017; Roberts et al., 2018) but the challenges  
76 faced by carers during chemotherapy have not featured. Few interventions have been developed to  
77 address carer needs during chemotherapy (Tsianakas et al., 2015).

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

85

## 86 **2. Methods**

### 87 *2.1. Design*

88 A longitudinal qualitative design was adopted, entailing digitally-recorded semi-structured  
89 interviews conducted with family carers at three points during patients' treatment with intravenous  
90 chemotherapy: start of treatment (T1), mid-point (T2) i.e. point where half of the planned cycles of  
91 chemotherapy had been administered, and completion of chemotherapy (T3). Interviews focused on  
92 carers' need for information and support from healthcare professionals and factors that affect their  
93 confidence and competence in caring for someone over the course of chemotherapy. Analysis of  
94 longitudinal data can provide rich understandings of changes and/or stability over time, factors that

95 may account for these, and both how and why experiences may vary between individuals (Saldaña,  
96 2003; Calman et al., 2013).

97

## 98 2.2. *Participants*

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

112 Twenty-five participants were sought. This sample size reflects recommendations that  
113 qualitative researchers interview fewer than 50 interviewees (Ritchie and Lewis, 2003) in order to  
114 maintain quality of data collection and allow in-depth analysis. Further, it is suggested that limited  
115 new information is revealed when more than 25-30 participants are interviewed (Hennink et al.,  
116 2017). In this study, the research teams in Southampton and London reviewed collectively the data  
117 every two weeks to establish the point at which no new information was being generated -  
118 information that would either enhance or alter the study findings – indicating that data saturation



119 had been achieved and data collection could cease. Data saturation was achieved at each time point  
120 despite fewer interviews being conducted over time (see findings).

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

125

### 126 *2.3. Qualitative interviews*

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

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

140

### 141 *2.4. Data analysis*

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

150 [insert Figure 1 here]

151

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

161

### 162 **3. Findings**

163 One hundred and one patients were screened for eligibility and 64 eligible carers were  
164 approached about the study in order to consent 25 carers as planned. Five carers withdrew before

165 the second interview, and a further two before the third. Withdrawals followed deterioration in  
166 patients' health or their death (see Figure 2).

167 [insert Figure 2 here]

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

172 [insert Tables 1 and 2 here]

173  
174 Data analysis identified three themes that which reflected carers' experiences and support  
175 needs over time: *Changing lives, Changing roles; Confidence in caring, and Managing uncertainty*.  
176 These themes endured over time but some aspects of them – sub-themes – varied as treatment  
177 progressed and patients' needs altered. Some appeared linear with trends (either improvement or  
178 decline) over time, whilst others had no evident pattern. Some differences in carer experience were  
179 evident according to the intent of patients' treatment (curative versus palliative) (see Table 3).

180 [insert Table 3 here]

### 181 3.1. *Changing lives, changing roles*

182 The first theme indicates how, across time, carers' lives changed as did the roles they  
183 undertook in supporting patients. Carers found that they rapidly (from T1) had to undertake more  
184 roles within the home as many relatives' felt the immediate effects of treatment. These obligations  
185 grew with time (T2 and 3) and many carers felt accompanying stress. The changing domestic  
186 dynamic appeared to have a knock-on effect that was felt more keenly over time (by T2 and T3) on  
187 relationships with some becoming stronger and others frayed. Concerns over financial stability were  
188 constant (present from T1 and persisting to T3) and influenced by working carers' decisions to

189 decrease (due to caregiving requirements) or increase (due to financial need) employment as  
 190 needed. A balance was evident for those of working age – between caregiving and working - that  
 191 was challenging for some to achieve.

### 192 3.1.1. *You doing everything*

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

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

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

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

210 It was clear that the stress felt by carers, created by caregiving during chemotherapy, did not abate  
 211 with time. A high level of unremitting stress, that commenced when chemotherapy started, was felt

212 by all carers. The burden of helping to manage patients' treatment and the associated disruption to  
213 carers' lives appeared to increase with time.

214

### 215 3.1.2. Impact on our interactions

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

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

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

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

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

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

242

### 243    3.1.3. *I'm the breadwinner*

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

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

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

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

259 commitments were often driven by reduced financial circumstances due to patients' inability to  
260 work.

261

### 262 *3.2. Confidence in caring*

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

#### 269 *3.2.1. We weren't sure if it was a problem*

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

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

280

#### 281 *3.2.2. You know what to look out for*

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

284 *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*  
 285 *a problem and what isn't too much of an issue, and just getting used to it, I think. (C11, 27, F,*  
 286 *girlfriend)*

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

### 293 3.2.3. Doing it all the time

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

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



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

309

### 310 *3.3. Managing uncertainty*

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

#### 318 *3.3.1. Steel myself for anything*

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

323           *Well I thought to myself well I'd better steel myself for anything here because I don't know*  
324 *how it's going to affect her every day, and I was getting a bit concerned about whether she*  
325 *would be able to, would she be in a state to be at home on her own if I was working. (C3, M,*  
326 *63, husband).*

327           For some, concerns over disease recurrence appeared at the root of their anxieties; they  
328 were concerned that their relative would undergo unpleasant side-effects and risks of chemotherapy

329 without attaining the intended remission from disease. Three carers of people having curative  
 330 chemotherapy reported physical complaints at T1 which they related to stress.

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

338

### 339 3.3.2. Taking control

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

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

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

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

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

361

### 362 3.3.3. *How do we get to the other side?*

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

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

373 As one carer articulated, her worries were 'always going to be there' in the future as  
374 monitoring and check-ups continued (C8, F, 51, mother). After the routine of treatment and

375 structure of appointments, there emerged a return to uncertainty – as one participant explained,  
376 there was an acute sense of uncertainty over ‘what does the future hold?’ (P8, 33, F, daughter).

377

#### 378 **4. Discussion**

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

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

400 suggesting that healthcare professionals need to be proactive at this time, as well as revisiting issues  
401 related to work later on.

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

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

418           It was also noteworthy how the outlook and perceptions of chemotherapy held by our study  
419 participants – as either a treatment to be feared or one offering hope – differed according to  
420 whether chemotherapy was being given to prevent recurrence or as a palliative measure.

421 Additionally, carers' views on transition to life post-chemotherapy varied markedly although all were  
422 characterised by uncertainty, at marked odds to feelings of control generated by the routine of  
423 treatment. For carers of people having curative treatment, fear of recurrence was evident. For those  
424 caring for people completing palliative treatment, uncertainties predominantly centred around the

425 length of time before disease would progress and their – and patients’ – likely resilience as end of  
426 life neared. The literature increasingly refers to patients’ fear of recurrence and this concept is  
427 relatively well-researched (Armes et al., 2009); however, the nature of fear of recurrence and/or  
428 progression held by carers is much less researched, with few exceptions (Hodges & Humphris, 2009).

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

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

441

#### 442 *4.1 Strengths and limitations of the study*

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

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

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

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

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

467

## 468 **5. Conclusions**

469 Chemotherapy is – and will remain – an important treatment for cancer for the foreseeable  
470 future and will continue to be delivered primarily in day care settings. This requires carers to take  
471 considerable responsibility for patient wellbeing at home. Carers play an important role in patient  
472 safety – recognising and responding to symptoms and knowing when to access help for acute  
473 toxicities which can lead to sudden patient deterioration. It is essential that healthcare professionals  
474 prepare carers and ensure that they are well equipped for, and supported in, caregiving in; this will  
475 help to safeguard patient safety. Carers' input enables healthcare services to operate and

476 contributes substantially to cost reduction at the end of life (Round et al., 2015) as patients and  
477 clinicians rely on carers' support and care management skills (McKenzie et al., 2017). This study  
478 suggests that some carers are at risk of becoming overburdened by requirements imposed by  
479 patients' illness, fear for the future and requirements of treatment. However, conversely carers can  
480 be very positive, upbeat and manage caring without detriment to their own wellbeing. Thus, it is  
481 important that they have their caring ability and needs assessed, particularly as they may be  
482 reluctant to ask for support (Renovanz et al., 2018). The demands on them – and their needs for  
483 assistance – are often overlooked (Ussher et al., 2009). Given the dynamic nature of carers'  
484 experiences, this study suggests that their needs should be assessed periodically.

485

486       Finally, as indicated in previous research focusing on cancer carers' needs (Ream et al.,  
487 2013), this study points to the need for carer interventions that prepare carers for, and sustain them  
488 during, caregiving. Such interventions need to be pragmatic and feasible to deliver in what is  
489 effectively a clinical busy setting. One intervention – Take Care<sup>®</sup> – reported in the literature outlines  
490 the potential of a brief educative intervention for enhancing carers' self-efficacy for caregiving  
491 during chemotherapy (Tsianakas et al., 2015). It is the only intervention written about in the  
492 literature developed specifically for supporting cancer carers during this time. This is clearly an area  
493 that needs greater research and development in future.

#### 494 **Conflicts of interest**

495 None declared.

#### 496 **Ethical approval**

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

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641 **Figure 1. Extracts depicting data analysis process**642 **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	<b>T1:</b> Finding it very tiring combining work and caring responsibilities <b>T2:</b> 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. <b>T3:</b> No data – no interview possible
C6	M Curative	Wife	<b>T1:</b> Has had to use annual leave to accompany husband to hospital. Only two days paid leave left. <b>T2:</b> Still working, employers really supportive allowing her to take time off as required. Annual leave nearly run out. <b>T3:</b> Continuing working. Taking unpaid leave as needed.
C11	M Curative	Girlfriend	<b>T1:</b> Not working. Appears overwhelmed emotionally, exhausted. Recognises if did work she's unsure how she would accommodate chores, caring responsibilities as well as job <b>T2:</b> Mentions she is a procrastinator. Wants to look for work, but finding it hard to get motivated to do this. <b>T3:</b> 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	<b>T1:</b> 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. <b>T2:</b> Livestock have been moved closer to home so that she can keep an eye on them more easily. <b>T3:</b> 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	<b>T1:</b> Not working <b>T2:</b> 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. <b>T3:</b> 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'.

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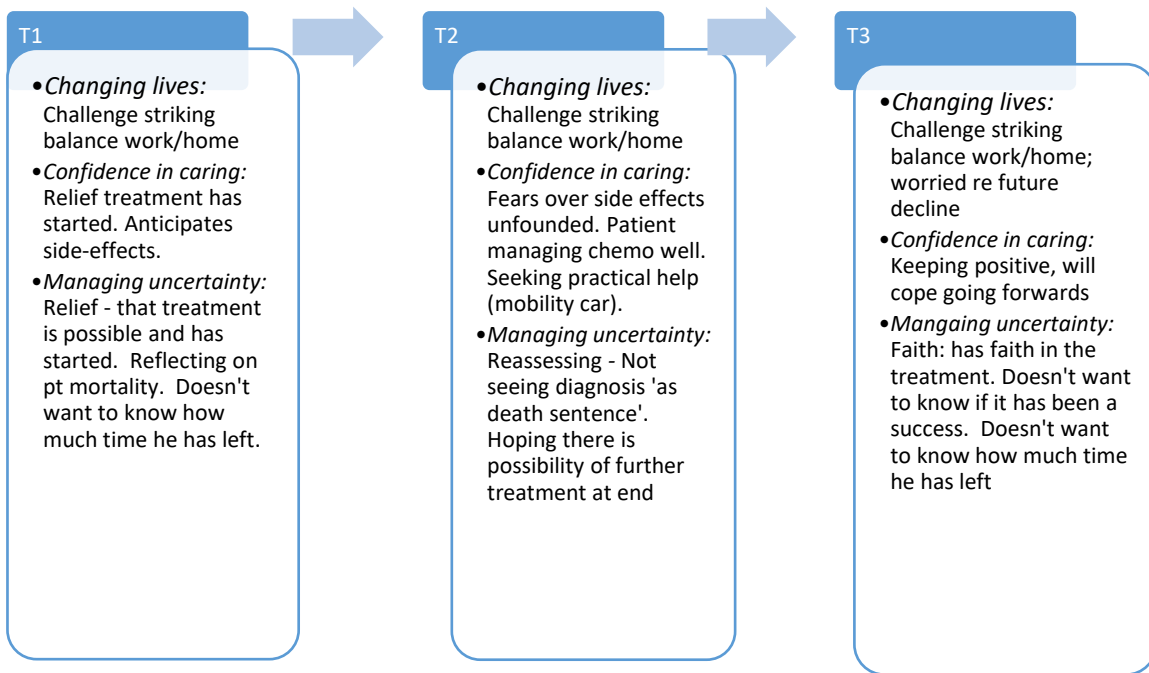
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648 **1b: Example of mapping over time for Carer P1**



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**Figure 2: Flow of participants through the study**

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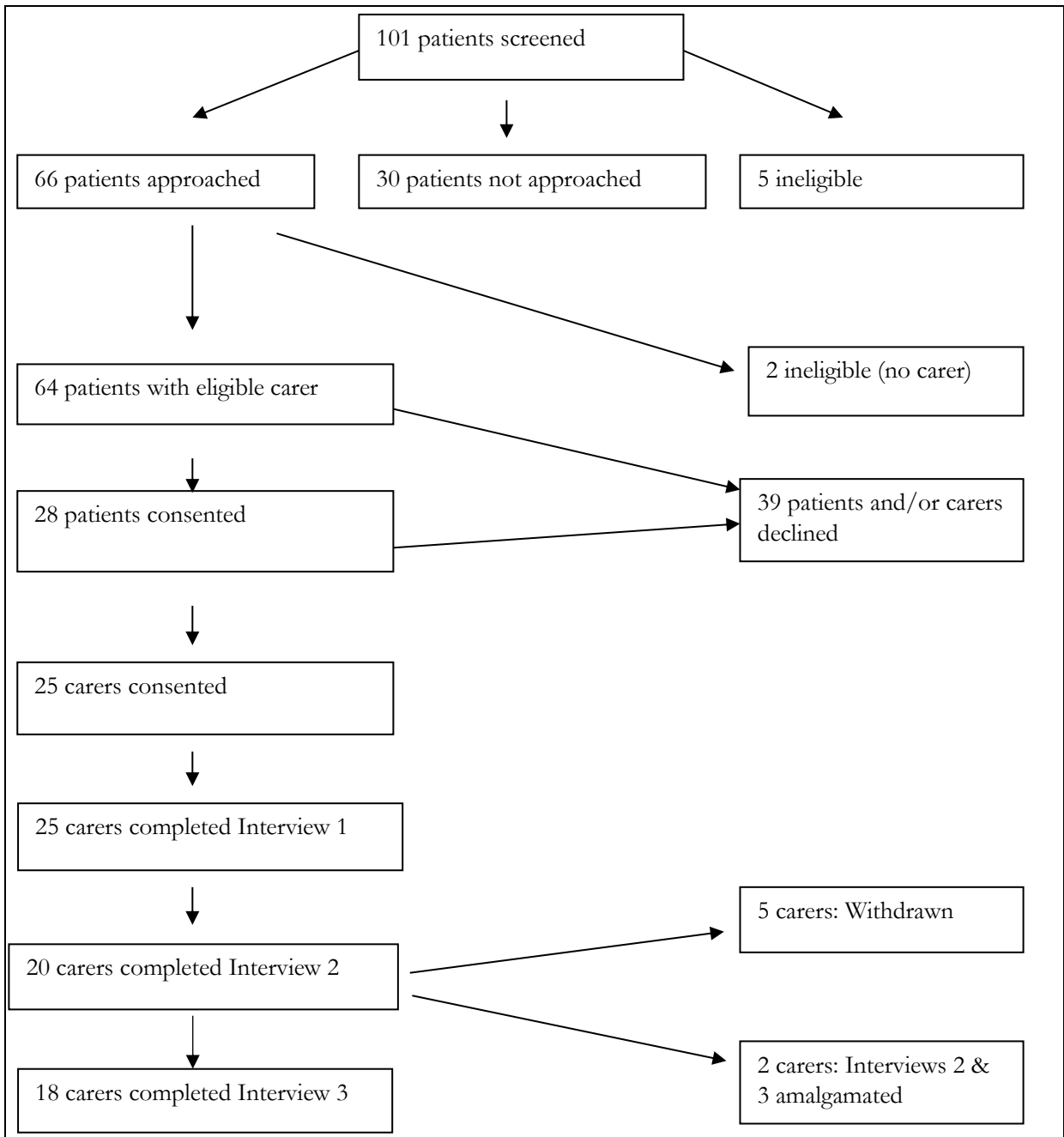
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676 **Table 1. Characteristics of carers recruited to the study**

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

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679 **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

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

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

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