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ORIGINAL ARTICLE

What are the sources of distress in a range of cancer caregivers? A qualitative study

Jo Taylor[1,2,3] · Elizabeth Fradgley[1,2,3,4] · Tara Clinton-McHarg[2,3,5] · Emma Byrnes[1,6] · Christine Paul[1,2,3,7]

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Abstract

Purpose Caring for a person diagnosed with cancer is associated with elevated distress that may impact on caregiver health and patient outcomes. However, caregivers' distress is relatively under-researched. This Australian study explored a range of caregivers' reported sources of distress.

Methods The grounded theory approach informed semi-structured interviews that were conducted with a purposive and broad range sample of distressed caregivers identified through the 'Structured Triage And Referral by Telephone' (START) trial. A grounded theory framework was used to generate themes with data analysed by two independent coders using the NVivo software.

Results Caregivers ($n = 14$) were aged from 25 to 80 years, including two bereaved caregivers. The relationships of the caregivers to the patients were as follows: partner ($n = 8$), parent ($n = 1$), child ($n = 3$), sibling ($n = 1$), and friend ($n = 1$). Six major themes emerged in relation to sources of distress: (1) a lack of sufficient and timely information; (2) uncertainty; (3) the role and duties of caregiving; (4) lack of family-centred services; (5) practical challenges; and (6) impact of distress.

Conclusion Caregivers face a number of specific challenges beyond those experienced by patients. It is essential to ensure that caregivers are actively well-informed and well-supported alongside the person who is diagnosed with cancer.

Keywords Cancer · Caregiver · Distress · Qualitative

Background

While there is no clear consensus on the definition of a caregiver [1], caregivers often routinely provide assistance and support of both a physical and a psychological nature, to a family member or friend with an illness or disability. A caregiver self-identifies and is usually also identified by the patient as playing an instrumental role in providing support [2–6].

Treatment for cancer patients has transitioned from largely inpatient to outpatient care. As such, the breadth of caregiving needed by people diagnosed with cancer has grown [7]. In Australia, one in eight people are providing some informal care [8]. Support from caregivers improves patient outcomes and has been associated with patients': adherence and completion of treatment; levels of depression and anxiety; and overall well-being [3, 9–12]. Caregivers are now an essential component in the system of healthcare delivery [3] and efforts to mitigate caregiver distress are necessary.

Caregiving includes numerous home-based care responsibilities [13], heightening the need for accessible information

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✉ Jo Taylor
jtaylor1@newcastle.edu.au

[1] School of Medicine and Public Health, University of Newcastle, Level 4 West, HMRI Building, Callaghan, NSW 2308, Australia

[2] Priority Research Centre for Health Behaviour, University of Newcastle, Callaghan, Australia

[3] Priority Research Centre for Cancer Research Innovation and Translation, University of Newcastle, Callaghan, Australia

[4] Cancer Institute New South Wales, Eveleigh, Australia

[5] School of Psychology, University of Newcastle, Callaghan, Australia

[6] Priority Research Centre for Generational Health and Aging, University of Newcastle, Callaghan, Australia

[7] Hunter Research Cancer Alliance, HMRI Building, New Lambton Heights, Australia

and support, both in the healthcare setting and at home [14]. Previous literature suggests that unmet needs for caregivers may include assistance with as follows: psychological distress; health literacy; physical health; family support; financial impacts; and practical difficulties [15]. Caregivers can experience increased risk of cardiovascular disease and stroke following a patient's cancer diagnosis and are often older and in poor physical health [16]. Additional challenges such as role transitions from partner to caregiver bring new responsibilities and include decision-making and planning for patients' changing needs, alongside managing transportation time and cost [17].

The often longitudinal nature of cancer brings with it the potential risk for caregivers to experience high levels of distress and physical decline [16, 17]. Elevated distress among caregivers can be commensurate or exceeding that of the patients they care for [18–21], and up to 40% have reported ongoing distress [22, 23]. Previous studies have found that age, gender, and lower income were associated with distress in cancer caregivers [24]. However, these studies were often limited to focus on spousal caregivers and common tumour types. In previous qualitative studies, importance of information, financial impacts, and disruption to life themes related to distress emerged [25–27]. However, these previous studies were tumour specific [27] and only focused on acute or palliative stages of disease [24]. No studies to date have conducted an in-depth qualitative exploration of the sources of caregiver distress in a range of caregivers. Given this gap in the literature, the current study aimed to gain an in-depth understanding of caregivers' sources of distress, from a wide range of different caregiver perspectives at various stages of disease, including bereavement.

Method

Design

The grounded theory approach [28] informed semi-structured, in-depth interviews that were conducted individually with a purposive sample of caregivers of cancer patients, who were participating in the Structured Triage And Referral by Telephone (START) trial from May to September 2019 [29]. The START trial is a cluster randomised stepped-wedge study exploring the effectiveness of structured distress screening and management versus usual care delivered by Cancer Council Information and Support services in Victoria and New South Wales.

Participants and procedures

Eligible participants were the following: an identified caregiver of a person diagnosed with cancer; a score of 4 or more on the Distress Thermometer (DT); a New South Wales or Victorian resident; 18 years or older; proficient in English. Given only distressed caregivers (as measured by the DT) were eligible to participate in START, this ensured all interview participants were able to comment on some source of distress. After completing a 6-month START telephone interview, caregivers were invited to take part in a further telephone interview. Caregivers from both intervention and usual care arms of the START trial were approached as the intervention had been delivered more than 6 months prior, was not related to the interview content (i.e., sources of distress), and therefore was unlikely to influence caregivers' recent experiences. Maximum variation sampling was used to select a broad range of participants across gender, age, rurality, distress level, relationship status (e.g., married), and relationship to the patient, using data from START participant interviews. These variables were selected primarily on the basis of demonstrated association with increased caregiver distress or unmet needs [22, 30, 31]. Cancer type and stage were not feasible to include. Sample size was reached when all categories and variables were represented by at least one participant (participants were able to fulfil more than one variable). Due to ethical regulations, individuals who declined to participate were not asked to provide a reason.

Data collection

A semi-structured interview guide was pilot tested (JT) with research team members and the first interview participant. Interview questions were focused on exploring the sources of caregiver distress (Table 1). Open-ended questions and prompts were used that allowed participants to volunteer information and explore other issues in more detail according to their preference, for example changes to employment. Interview questions or data focused on other issues related to distress and support are reported elsewhere and are beyond the scope of this research question. All interviews were audio-recorded, conducted by a trained female research team member (JT), and supplemented by field notes [32]. Saturation of themes was assessed throughout data collection and was reached after fourteen interviews. Specifically, our method for assessing saturation was weekly team review of interview data; iterative regrouping of interview data into themes; and once no new thematic data emerged, one additional interview was conducted for rigour.

Data analysis

The grounded theory framework was used to guide theme generation [28]. Audio-recordings were

Table 1 Interview guide for caregivers

Interview Guide for caregivers' perspectives on their own distress	
Distress screening and checking in	Have you been asked about your distress levels throughout your significant other's cancer journey? *Prompts: If yes, location, setting, asked by, frequency?* Has being asked about your distress been helpful? *Prompts: If yes, description, if no, description.* How often do you feel would be helpful to be asked about your levels of distress? *Prompts: Treatment centre based, outside of a treatment centre—weekly, fortnightly, etc.* *Preference for calling a service or receiving a call.*
Levels of distress	Can you tell me about your distress levels while caring for your significant other? *Prompts: Specific time or triggers for distress*
Source of distress	Has there been a main source of distress for you throughout this experience? *Prompts: Physical, emotional, practical, patient needs, own needs, family responsibilities*

Additional questions exploring other areas of interest were part of the interview and are not presented here

'Significant other' is the ethically approved term for caregivers in the interview

transcribed verbatim by external professionals. Two independent coders (JT and EB) analysed the transcriptions using the NVivo software. The analysis process was guided by the method of thematic analysis [28, 33], involved a line-by-line review, and used inductive reasoning [34] to generate a contextualised list of themes. A progressive manual was developed to code transcripts that enabled a constant comparative process of analysis. Discrepancies between coders were discussed until agreement was reached.

Results

Recruitment and consent of the 14 study participants is reported in Fig. 1.

Demographic characteristics of this diverse caregiver sample included gender, age, rurality, distress level, relationship status, and relationship to the patient and are detailed in Table 2.

Themes

Thematic analysis identified six themes related to sources of distress which are presented in Fig. 2 and discussed separately with illustrative quotes. Direct quotes are identified only by participant number and gender to avoid potential for participant re-identification. Additional quotes are reported in Supplementary Table 1.

Lack of sufficient and timely information

Information was a universal area of need which impacted caregivers' distress during the cancer diagnosis:

> …for me information is power, to be able to cope with situations, to know what you're expecting… (P3, female).

Caregivers reported a lack of information being communicated clearly from the most appropriate person:

> …I don't know whether they were deliberately just releasing a little bit of information at a time or not… (P9, male).

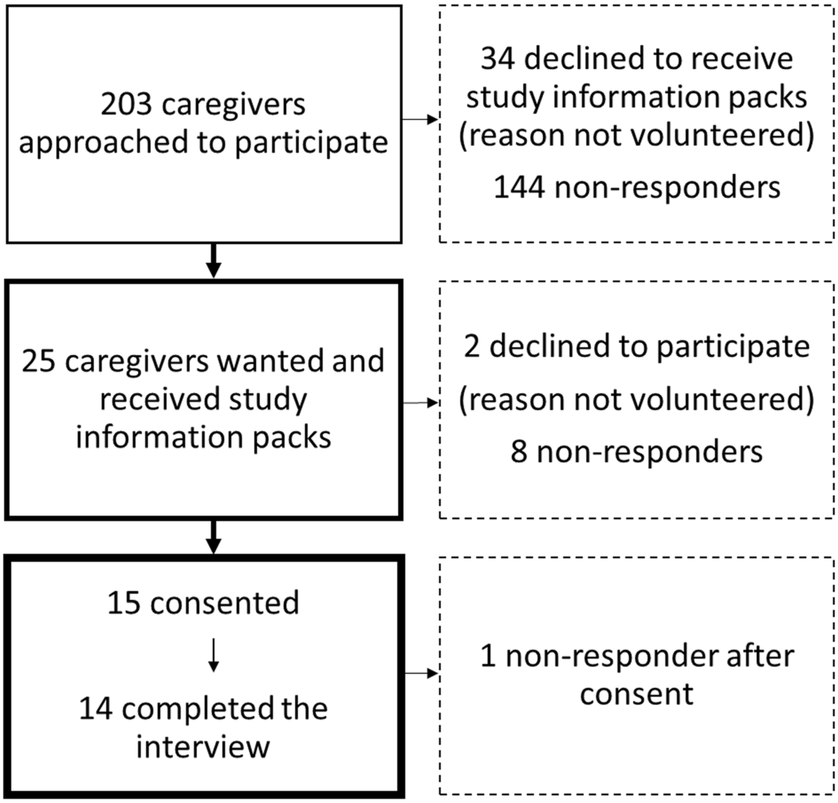
The need for timely and sufficient information changed over time from diagnosis to treatment and from treatment to post-treatment; palliative care or bereavement was experienced by one participant:

> …it was just like a treadmill, everything was suddenly…happening…there were a lot of miscommunications along the line… (P7, female).

Unexpected responses to treatment caused great distress when timely information was not available or communicated as one caregiver experienced:

> ...just the lack of relations [with health professionals]… that was pretty distressing… (P9, male).

Fig. 1 Study recruitment and consent



At treatment to post-treatment, information on recovery was wanted:

> …more information on recovery would be really useful and the length that recovery takes… (P7, female).

Palliative stages often changed the type of information caregivers were looking for:

> …what would be really useful is if there was…a death counsellor… and talk to someone about what happens when somebody dies? (P8, female).

Uncertainty

Throughout the stages of disease, uncertainty was present and often linked to the immediate challenges being faced, with many acknowledging that this may be a constant throughout the caregiving experience:

> …the unknowing, I suppose, there's always the thought that it's not going to work… (P6, male).

Waiting in itself presented challenges for caregivers when supporting their loved ones through tests and appointments:

> …not knowing what you're in for until you've got your results, that was the hard part… (P10, female).

Surveillance-related uncertainty was experienced by one caregiver whereby the absence of active treatment prevented the opportunity to be connected with pathways for emotional support provided in treatment centres:

> …we didn't know …the progression of it… if there was a timeline… we knew very little, I was preparing myself, what to do, worst case scenario… (P2, male).

During treatment, uncertainty was spoken of in relation to additional decisions and unknowns. There was a sense of a never-ending process that revealed itself in stages:

> …there's no way you can get rid of those unknowns because cancer is so individual... (P7, female).

The post-treatment phase also raised continuing uncertainty:

> …no one's going to say, at the end of five…or…ten years, you're completely free of it… (P6, male).

Table 2 Caregiver demographic characteristics

Demographic characteristics		
		$N = 14$
Age (25–85)	25–35	1
	36–45	2
	46–55	4
	56–65	4
	66–75	1
	76–85	2
Gender	Male	6
	Female	8
Distress level (6 months prior to interview)	Distress Thermometer score μ	6.3
	Range	4–9
Caregiver relationship to patient	Partner	8
	Child	3
	Parent	1
	Sibling	1
	Friend	1
Living arrangements	Living with patient	8
	Not living with patient	6
Bereaved	Bereaved	2
	Not bereaved	12
Geographical location	Rural	5
Caregiver relationship status†	Partnered (married, de facto)	13
	Not partnered (single, divorced, widowed)	1
Education	School (≤ 12 years)	6
	Tertiary (≥ 12 years)	8
Tumour type of patient	Blood	4
	Breast	2
	Colorectal	1
	Head and neck	1
	Lung	1
	Pancreatic	2
	Prostate	1
	Stomach	2

† Caregiver relationship may not be to the patient

Caregivers facing palliative stages spoke of the physical aspects of dying, and their need for specific information to mitigate their uncertainty was experienced by one participant:

> … they're on their last breath, it's a weird thing where we don't know what to expect…are they in pain? (P8, female).

Role and duties of caregiving

In relation to the nature of the caregiving role, specific time points across the disease spectrum were not generally mentioned. Decision-making on behalf of the patient was commonly spoken about, with complications arising for patients and caregivers required to assess whether a trip to the emergency department is warranted:

> …as the caregiver you're the one there probably trying to make the call about it all... (P14, male).

Diagnosis posed challenges of shock and being asked to make important decisions quickly, including how this was communicated:

> …it was almost too quick, because we didn't have time to absorb the shock of what was happening… (P1, female).

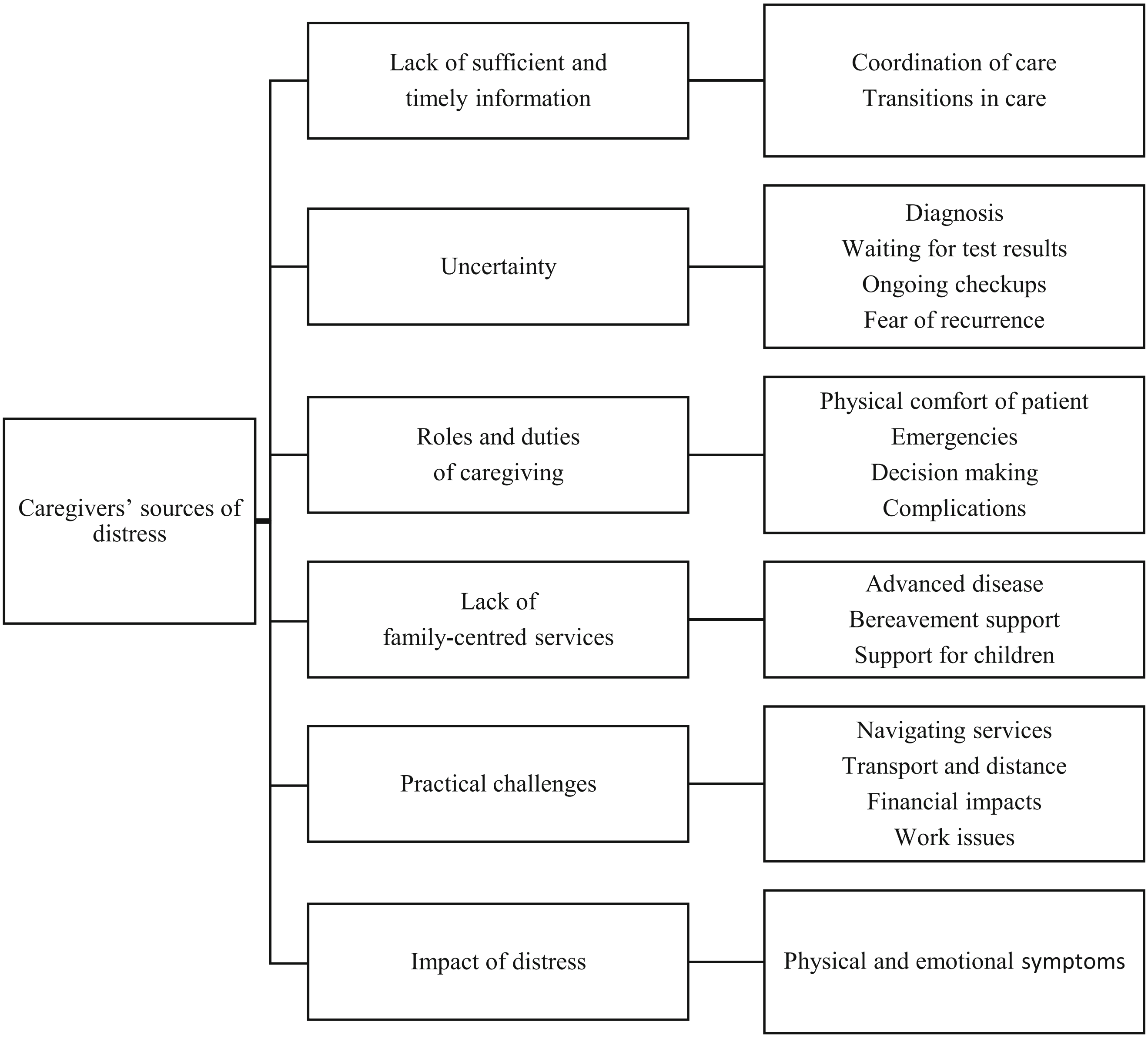


Fig. 2 Caregivers' sources of distress themes and sub-themes

Caregivers spoke of their investment in positive results and the sense of wishing things were favourable for their loved one. Given the caregiver's role as a go-between, there was awareness that had the results not been positive; this news would have been potentially difficult to share:

> …we were getting positive results, I found that cheerful to let them all know, but I would've had difficulty if it was the reverse, to be honest… (P10, female).

Caregiver's responsibilities extended across multiple commitments, and the sense of not being able to adequately fulfil all their caregiving roles was illustrated in terms of the experience exceeding their capacity:

> …My husband had…chemo every two weeks,…in the middle, I've got a sister who's blind and in care…in the spare time I… did have, I would go and see her, but she missed out on a lot… (P1, female).

Caregivers reported that their experience of emotional distress was tied to the patient's physical comfort. This included discomforts related to treatment, recovery, and ongoing deficits as a result of treatment or the disease:

> …It was very distressing seeing my husband, so sick….really immobile…that was really confronting, and when he couldn't eat, because he had so many ulcers… (P11, female).

During the treatment phase, caregivers described the experience of liaising with multiple health teams. The absence of a central person to help navigate this phase was experienced by one participant:

> …there is no coordinated approach between all the different disciplines and the patient… you feel like there's no one actually driving the case…who's meant to be following up?... coordination needs to be improved… one constant person that can be the link... (P4, male).

At post-treatment and discharge, support from the caregiver was often required and was unexpected in nature, specifically the level of medical care to be provided by a caregiver. The lack of preparedness and skills required for this specialised care was a shock and a source of distress:

> …I think, although confronting in hospital, it was much harder when he came home…he had a fall one night… (P7, female).

Lack of family-centred services

Information or access to support for children affected by cancer was a large source of distress for parents who needed specific information for communicating with children across the disease trajectory. Information was often lacking and difficult to locate:

> …when my wife was diagnosed… we have four kids, I was trying to find information on what you tell your kids… (P2, male).

Caregivers' experiences when accessing services for their children in a hospital setting were complex, involving lack of information and poor availability of psychological services to support the emotional needs of children after a parent received a cancer diagnosis. This resulted in participants needing to interact with a diverse range of providers simultaneously to source important support for their children:

> …the hospital wouldn't speak to her, the hospital counsellor; she was too young...she was old enough to know what was going on… it was very, very frustrating; it was awful… (P11, female).

Services often lacked clear pathways in their efforts to support children emotionally, leaving parents unsure where to access appropriate services and seeking multiple options to obtain sufficient support:

> … we've been to see a couple of child psychologists… the outpatient mental health services run specifically for kids, and they weren't really sure either… (P11, female).

Caregivers were often charged with locating support options during bereavement:

> …I didn't use it, but… it was good to know it was there…they actually have grief counselling… (P8, female).

Ongoing support from services was also needed as described by one caregiver:

> …how are you managing now, I think that would be really nice… (P13, female).

Practical challenges

Distress was reported in relation to the logistics and the practicalities of day-to-day treatment and recovery phases.

Caregivers reported difficulty wading through the specifics of eligibility for assistance from different services, with the process often being lengthy and time consuming:

> …it's very difficult to work out how you can get help, what help you're entitled to…a lot of legwork… (P12, male).

Challenges included loss of income, time away from work, costs of treatment, associated travel, and recovery. Financial impact was apparent for those raising families; however, all caregivers spoke of the impact:

> …two years later and we are still recovering financially… and the stress associated…it adds to the mental anguish of the situation, absolutely… (P11, female).

Transportation to treatment raised distress, for those travelling larger distances whether residing at a distance from the treatment, the patient, or both. Distress was related to travel time, transportation availability, transport co-ordination, and the caregiver's capacity to accompany a patient to treatment or visit if hospitalised:

> …I was travelling with community transport every second day…that's two hours up, two hours back…I was limited to how much time I had with him… (P7, female).

Impact of caregiver distress

Caregivers described the impact of their distress and the impact of this distress on their well-being that was physical and emotional, involved shock and related to daily functioning. Caregivers experienced this as debilitating inertia for some, new physical ailments and anxiety that presented as panic attacks for others:

> …it turns out that, that stomach component I had was stress related… I did… have it… before when my Dad was diagnosed but didn't know… (P2, male).

Other experiences were emotional in nature:

> …Mum and I are very close… instantly life-changing… I probably get angry more often than sad… (P3, female)

With the shock of a diagnosis challenging life's story moving forward:

> …it was very tough…we'd known each other for life… very close... (P8, female).

Caregivers spoke of the disabling effects of a cancer diagnosis:

> …I could not manage anything... zero, absolutely nothing at that point… I was completely helpless… (P11, female).

In addition to the impact of their distress, caregivers also indicated that efforts from others can ameliorate the distress to some degree:

> …you're in shock... so having someone who reaches out to you is incredibly powerful... (P14, male).

Although many expressed profound levels of emotional distress, caregivers were not routinely asked how they were coping when attending treatment centres and many considered concern for their welfare a form of support:

> …it feels very nice to be asked… on how are you going…it really is a nice, warm feeling… (P2, male).

Discussion

Six themes emerged as sources of distress for cancer caregivers: a lack of sufficient and timely information; uncertainty; the role and duties of caregiving; lack of family-centred services; practical challenges; and impact of distress. While several sources of distress are represented in previous literature [16, 17, 35], additional sources of distress were revealed in this study such as multiple roles and caregiver liaison.

Lack of information was a source of distress for caregivers across all stages of disease and has been documented previously [36, 37]. Other sources of distress such as uncertainty or practical challenges were amplified where information was not accessible. Caregivers indicated that the presence of sufficient, timely information would have allowed them to be more prepared for the challenges they were facing and to be assured of ongoing help into the future. This study extends our understanding by highlighting the importance of information being sufficient, timely, well communicated, and spanning the disease spectrum [26, 36]. The availability of a dedicated liaison to assist caregivers with information and contacts was varied. Forster et al. [26] previously reported that caregivers' level of information can be linked to a patient's willingness to include the caregiver, which we did not specifically explore. This study's findings suggest that an ongoing liaison point for caregivers could provide an important type of support not clearly identified previously.

Uncertainty was spoken of in relation to the patient's circumstances rather than that of the caregiver. It is likely that a caregiver's focus may initially be consumed by the patient's changing needs while the caregiver's needs may surface over time. Caregiver uncertainty in relation to their own needs was expressed in relation to end-stage disease; speaking of the arduous nature of caregiving and exhaustion, this finding is consistent with previous studies at palliatives stages [24].

This study revealed caregivers' views that their role was inherently stressful due—at least in part—to the limited capacity of health systems to support patients and include caregivers. Participants reported that the role of caregiver demanded skills in coordination of care for the patient, particularly during treatment. Within this phase, maximising physical comfort and managing emergencies were challenges faced by caregivers with limited previous experience. Caregivers spoke of their prior thoughts of what the caregiving role entails and the often assumed acceptance of the role. This has not been explored within cancer; however, in age-related caregiving, up to 44% reported a lack of choice [38].

Caregivers experienced additional obstacles when seeking family-centred care. Those caregivers who were parenting children experienced difficulty in accessing psychological services due to availability, eligibility, or affordability. The search required information gathering and time and has not been previously explored for caregivers.

Bereavement itself was expressed as another stage of disease for caregivers with previous research focusing on grief support [24]. During bereavement, there was a lack of information on what to expect in the final stages of disease and a need for continued support, for services to taper rather than cease abruptly.

Practical challenges were a source of distress for caregivers, in particular, financial. Caregivers adjusted work commitments to meet treatment schedules and absorbed additional household responsibilities and expenses. Financial impacts and physical comfort for the patient were paramount during treatment and post-treatment phases with transport and distance proving difficult throughout diagnosis and treatment. These findings align with previous studies [24, 37].

Transport and distance were additional costs experienced by caregivers. Previous studies reported the need for free parking, medication, and accessible region-based treatment as ways of reducing financial impacts [16]. Distance compounded the experience for caregivers by removing them from their own social environments.

Caregivers reported distress and the impact on daily life is often not acknowledged, so too the long-term nature of caregiving; these longitudinal consequences for caregivers align with previous studies [24]. Houdin et al. report the disruption to life that caregivers experience [25]; this finding echoes similar experiences in this study speaking of the treatment phase as a full-time job.

Study implications

This study goes beyond what has been found before to offer important reflections on mitigating the distress experienced by caregivers. Firstly, sufficient information must be highly accessible to caregivers at multiple points along the disease spectrum, given their complex and sometimes multiple caregiving roles. Caregivers need access to information and resources for the other people they are supporting, such as children. Caregivers are the liaison between the patient and health system and need to be well supported in order to fulfil this essential role. Timely, adequate, appropriate, and sufficient information may reduce uncertainty and potentially distress.

Secondly, caregivers adopt a role where their own needs are considered secondary to the patient's needs. This implies that a pro-active approach is required to assist caregivers. Therefore, outreach support for caregivers is an area worthy of investigation. This is likely to be important for caregivers at advanced stages when care is likely to be intense and complex. Strategies which actively assist caregivers to cope with feeling out of their depth and under prepared for these challenges are needed. The themes found in this study are consistent with other research on screening checklists such as the 'family member problem checklist' [39] and distress thermometer problem checklist [40]. The inclusion of a friend's perspective in this study offers valuable new insights into their caregiving experiences in addition to family members. Screening checklists for caregivers need to ensure that family-reported outcome measures include both family members and friends.

Finally, further research into the multiple roles that cancer caregivers play is warranted as this is the first time this theme has emerged in the cancer caregiver literature.

Study limitations

These qualitative findings must be interpreted as indicative of individual caregivers' experiences rather than representative of all caregivers. Recall bias associated with self-report may be present. While saturation within this sample was reached with a broad range of caregivers, further sampling of other demographic characteristics (e.g. non-trial participants, Indigenous caregivers) and additional participants may have uncovered additional themes.

Conclusion

Caregivers face a number of specific challenges beyond those experienced by patients. It is essential to ensure that caregivers are actively well-informed and well-supported alongside the person who is diagnosed with cancer. This knowledge is likely to increase the capacity of services to provide more targeted support across the disease spectrum and potentially improve outcomes for both caregivers and the people they support.

Authors' contribution Jo Taylor, Elizabeth A. Fradgley, Tara Clinton-McHarg, and Christine L Paul contributed to the study conception and research question. Jo Taylor conducted the qualitative interviews. Emma Byrnes acted as the second coder for the double coding of interview transcripts. Data extraction and coding were conducted by Jo Taylor and Emma Byrnes. The first draft of the manuscript was written by Jo Taylor. Elizabeth A. Fradgley, Tara Clinton-McHarg, Emma Byrnes, and Christine L Paul commented on subsequent versions of the manuscript. All authors read and approved the final manuscript.

Compliance with ethical standards

This study was approved by the University of Newcastle Research Ethics Committee (H-2016-0180). The authors declare that they have no conflict of interest.

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