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ORIGINAL ARTICLE

Caring for the person with cancer and the role of digital technology in supporting carers

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Abstract

Purpose Informal carers may experience a range of unmet needs during the caring period and, at times, lack support to adequately manage care of the person with cancer and balance personal family and work commitments. The aim of this study was to understand the needs of informal carers of people with cancer and how digital technology may be used to address carers' needs.

Methods Focus groups and semi-structured interviews were conducted with 45 carers. Carers discussed supports and services they used to address their needs, barriers to accessing support, and how digital technology could assist in meeting their needs.

Results Carers used informal support such as friends and family and formal support including respite and community groups during the caring period. Barriers to accessing support included reluctance to seek external help, sensitivities associated with prioritising carers' needs over patients' needs, and the adequacy of information received. Technology was reported to have the potential to allow carers' privacy to seek support; however, carers' attitudes towards technology differed.

Conclusions Carers require support during the caring period to help balance their own needs with the needs of the person receiving cancer treatment. Digital technology may provide an opportunity to deliver support to carers; however, further research is needed to assess the appropriateness of these interventions to inform improved health outcomes for this vulnerable group.

Keywords Cancer · Carer · Digital technology · Support · Unmet needs

Introduction

In 2012, 14 million people were diagnosed with cancer worldwide [1]. In 2017, in Australia, approximately 130,000 people were diagnosed with cancer [2]. There is a greater need for informal carers in the community due to increased cancer survival [3] and earlier patient discharge from hospital in response to financial strains on health care systems [4]. Often, informal carers have limited information, skills, or resources to meet the needs of people with cancer [5].

Carers may experience unmet needs in their day-to-day lives such as difficulty balancing their own needs with those of the patient [5–7], the impact of caring on work and life activities [8, 9], and financial strain [7]. Finding and accessing support services for their own needs can be difficult for carers [5, 7].

Few studies have explored carers' preferences for delivery of support to address their needs [10, 11] and findings suggest of a variety of delivery modes may be needed to meet individual carers' preferences. Communication barriers between carers and healthcare professionals [6] and carers and patients can limit opportunities for carers to seek support for their own needs [7]. While there is some evidence that recent technologies may provide an opportunity for carers to overcome communication barriers and seek support when needed [12], current support methods and their acceptability need to be assessed first.

The findings reported in this paper derive from a larger study in which the overall aim was to explore the information, support and personal needs of informal carers of people with cancer, the adequacy of information and support received, barriers to accessing support, and how technology may be used to address carers' needs.

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Research questions

1) What difficulties are faced by carers when meeting their personal needs and accessing support services?
2) What supports and services do carers access during the cancer trajectory?
3) How can digital technology support carers?

Methods

Design

Carers' perspectives on support needs were assessed using a qualitative descriptive approach [13]. This enabled concepts from each participant's situation to be explored and to contribute to common concepts in data when developing themes [13]. Participants attended either a focus group or phone interview depending on their availability.

Sample

The sample comprised 45 carers. Recruitment ceased when data saturation occurred. Data were considered saturated when no new themes emerged between participant groups: current carers and past carers, or by recruitment method: focus groups and phone interviews. Participants were recruited from three sites: a public health service, a private health service, and a carer organisation.

Procedure At health services, carers were approached during patients' outpatient chemotherapy appointments. Carers recruited from the carer organisation responded to recruitment emails. Participants were provided with the option to attend one of two focus groups, or a phone interview if unavailable. All participants were informed of the overall purpose of the larger study. Informed consent was obtained from all participants included in the study.

Inclusion criteria Informal carers who were current or previous carers of someone receiving active or palliative cancer treatment (referred to as "the patient"), who were over the age of 18 and did not require an English language interpreter.

Data collection

Focus groups and phone interviews were guided by semi-structured questions that encouraged discussion about the experiences of carers in support and service use. A full list of topics is outlined in Table 1. The same topic guide was used regardless of the data collection method. Focus groups were facilitated by all authors and conducted within the carer organisation or health facilities in rooms separate from Day Oncology Units. Phone interviews were conducted with the researcher (NH) in a private room and carers in a location where they felt comfortable. Field notes were collected during or immediately following focus groups. Interviews and focus groups were audio-recorded with consent to enable full transcriptions.

Carers completed a short questionnaire to provide demographic information including age, gender, relationship to the person with cancer, level of education, and living situation.

Data analysis

Transcript data were coded manually and managed in the following sequence. Quotes were separated and organised into broad topics with subtopics. Subtopics were organised using a numbering system (coded and organised by NH). Initial analysis compared data obtained from focus groups with phone interviews to assess whether data collection methods impacted on findings. No differences between data collection methods were found by the research team and further analysis used combined data. Findings from current and previous carers were then analysed separately; no significant group differences were identified by the research team and the data were combined. To identify themes, coded data were analysed using deductive and inductive methods (analysis by NH and MB). Data obtained from focus groups and phone interviews were sorted and stored using Nvivo software and Microsoft Excel. SPSS software was used to run a descriptive statistical analysis to provide a summary of the demographic characteristics.

Findings

Two focus groups and 33 phone interviews were conducted. On average, focus groups ran for 77 min (range 74–80 min) and phone interviews for 39 min (range 20–73 min). Demographic data were collected from all participants and are reported in Table 2. Figure 1 provides a flowchart of the recruitment process.

The majority of carers (80%) provided information about the type of cancer their family member or friend was diagnosed with and has been summarised in Table 3.

Personal difficulties faced by carers and barriers to accessing supports

Carers experienced a variety of difficulties when juggling the needs of patients and other family members both on a daily basis and during times of crisis. Barriers to seeking support included hesitancy to seek help, sensitives such as guilt and reluctance to prioritise carers' needs over patients' needs, and a lack of knowledge of available services.

Table 1 Focus group and interview questions

1) Describe your experiences as a carer of a person with cancer.
2) How would you describe the challenges of being an informal carer?
3) Have you accessed any support services?
4) Thinking back to when your family member/friend first began treatment, what do you know now that you would have liked to have known then?
5) How have the health services supported you during this time?
6) How could digital technology such as smartphone applications support you while providing care to someone with cancer?

Juggling multiple demands to maintain a normal life

This theme related to maintaining the everyday and dealing with the unexpected. Carers' access to informal support networks varied depending on personal circumstances and availability of social and family networks. Carers reported difficulties balancing the needs of patients with paid work, raising children, and finding time for themselves while trying to "keep everything as normal as possible" (C8).

> There was an entire week during radiotherapy where we had to have our youngest taken to school every day [by others]. (C21)

However, when patients' care needs escalated, the availability of informal support networks were already exhausted or unable to be maintained over a prolonged period of time.

> I had two small children...we have no extended family… once or twice you can ask your friends to come round, when it is happening for 10 years you cannot keep asking your friends to come round, but you cannot keep dragging your kids to hospital overnight when they have to go to school the next day. (past carer focus group)

Table 2 Demographic characteristics of carers

Carer characteristics	Range	Mean
Age (years)	21–80 (SD = 14)	55
	Frequency (*n*)	%
Female	27	60
Carers relationship to patient		
Spouse	29	64.4
Parent	13	28.9
Other (relative/friend)	3	6.6
Lives with patient	39	86.7
Highest education level		
Primary school	1	2.2
High school	9	20
Cert. or diploma	7	15.6
University degree	21	46.7
Other	6	13.3

Reluctance to seek external help

Carers commonly prioritised their needs last and at times did not acknowledge that they had their own needs and this was a barrier to accessing support. Carers who were looking after someone throughout high acuity phases during intensive diagnostics, treatment, or death were attentive and responded only to the needs of patients.

> My focus is on him and making sure that, you know, he's comfortable and he does not feel like he's a burden on me. (C14)

Even when patients were comfortable with carers taking time off, carers still expressed reluctance in being away from the caring role. At times, this was due to a perceived sense of obligation in maintaining the caring role or the assumption that others would be burdened in providing care to patients while carers took time for themselves.

> C35: We have had a few people say "we can always take her" (to appointments), but I just want to do it…
> Interviewer: have you had any…personal time?
> C35: a little bit, only in the last couple of weeks, maybe just for a few hours… she's been pushing me to get back out and go for a ride

Sensitivities associated with prioritising carers' needs over patients' needs

There is little personal space for carers who are engaged in care relationships with patients with cancer. Several carers noted that while they experienced their own needs during the caring period, they were unlikely to address them. Carers were sensitive about directing attention to their own needs which created a barrier to seeking support and carers expressed concerns that this shifted the focus of care away from patients.

> I have been feeling guilty about feeling overwhelmed I just try and remember she has even more to feel overwhelmed with…I have to be strong. (C33)

For many carers, "the last thing you prioritise is yourself" (C34); as a result, carers were unlikely to voice their needs to others.

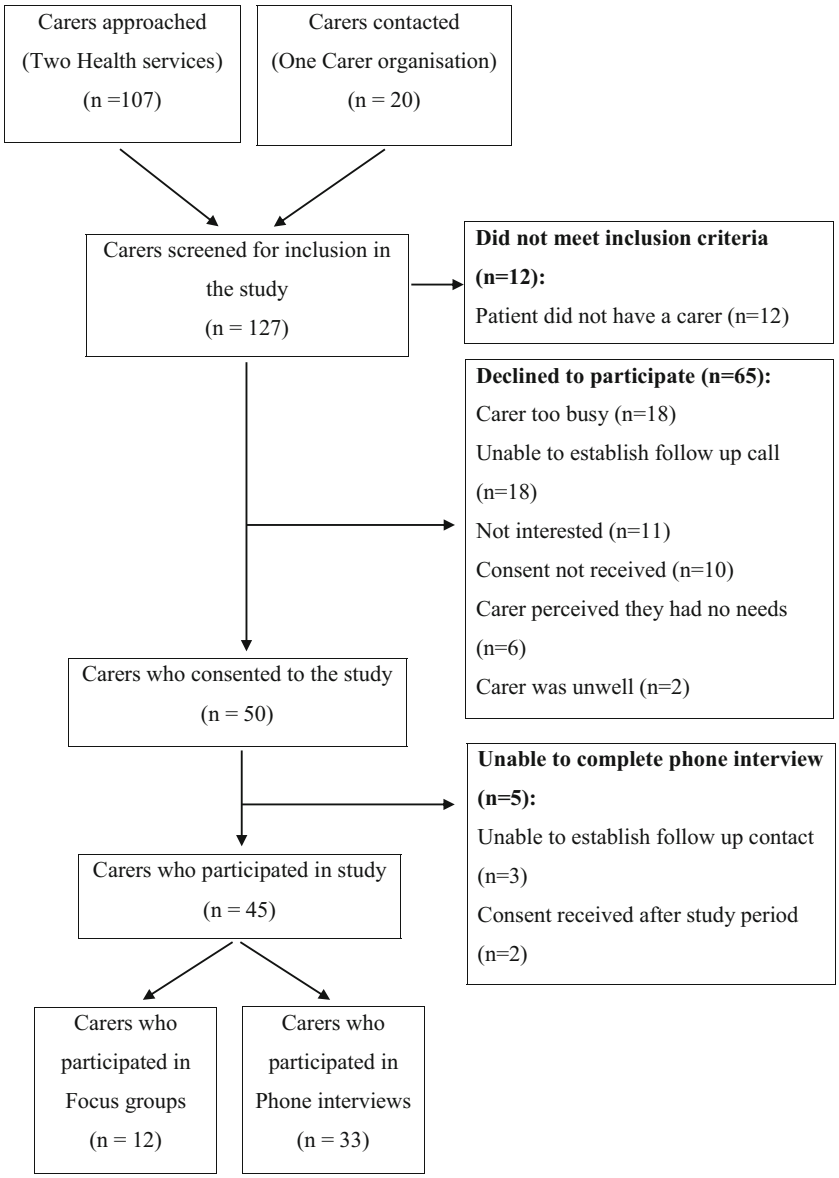

Fig. 1 Flow chart of recruitment process

> To me…it seems completely an inappropriate thing for someone who is there as a support person to (ask nursing staff) can you tell me where I can go and get some help? (C21)

Table 3 Cancer diagnoses of carers' family members or friends ($n = 36$)

Type of cancer	Frequency *n* (%)
Breast	11 (30)
Lymphoma/non-Hodgkin's lymphoma	7 (19)
Pancreatic	3 (8)
Leukaemia	3 (8)
Liver	2 (6)
Lung	2 (6)
Colorectal	2 (6)
Other (e.g. brain, prostate, stomach, multiple myeloma, bone, neck)	6 (17)

The concept of carers' needs being of low priority extended to carers' willingness to accept support from health services. When services were available carers were often reluctant to acknowledge they required assistance as they felt that "there is probably someone else out there that needs it more" (C28).

It was only when carers were "on the edge" (past carer focus group) that they recognised that their needs were of equal value to those of the patient and could impact on the quality of care they could provide.

> Not only am I trying to deal with dad's health issues I have got my own that are a result of dad's problems now. (past carer focus group)

Patients themselves could at times lack empathy towards carers' needs augmenting feelings of guilt among carers if they needed time away from the caring role.

> He put me through such a guilt trip, "oh you do not want me at home, you are putting me in prison (when using respite services)"… it was a lot of emotional blackmail from dad. (past carer focus group)

This hesitancy by carers to communicate their personal needs with patients and health professionals resulted in carers feeling isolated in their care unless support was offered through word of mouth or from others in a similar situation.

> One of those ladies (at a community group), she wrote down a list of carers' allowance, carers' payment companion card… had it not been for her I would have got nothing… because nothing comes from the hospital. (past carer focus group)

Inadequacy of information about service availability

When carers acknowledged their needs and were able to act upon them, the inadequacy of available information about services presented an additional barrier to accessing support. This could be due to poor knowledge of services available or a result of regular changes to services and carers' entitlements. Information seeking could often be time-consuming and frustrating and created an additional burden for carers.

> (About what services are available)… You do not know what you do not know, you feel stupid, you do not know what to ask, you do not know where to go, you do not know whose chain to rattle. (past carer focus group)

This was a common problem among first-time carers; past carers were more aware of the burden associated with caring for someone with cancer and were proactive in initiating access to formal support services.

> (Dad died from cancer)…seven years later when mum got it [cancer], I made sure this time that what I wanted, I was going to get, so the aged care team now that normally takes three to eight months, well that was done in two days. (past carers focus group)

Availability of support services was not standard across municipalities so carers found significant variance in entitlements dependant on their place of residence and city council. These inconsistencies increased carers' confusion and created a barrier to carers' ability to locate and access their entitlements.

> (Discussion during past carer focus group)
> C40: I'm in the City of G and because I live with mum…we do not qualify for any council assistance
> C39: we still qualified I had a cleaner come in every fortnight (carer shared a house with her father undergoing cancer treatment)
> C43: I asked for a cleaner, I was not allowed a cleaner. I was not allowed anything.

The role of technology

Technology was considered a possible solution to increasing carers' access to and awareness of services available. In discussing the role of technology, carers described ways that it could overcome some of the barriers associated with seeking support. In particular, technology allowed carers privacy to access information and personal support without the feeling that they were prioritising their needs. However, carers were not all in agreement that technology is the best solution for their unmet support needs.

The Internet enables carers' privacy in seeking information and support

Accessing support through technology allows carers to seek support for their personal needs without having to, or being perceived to prioritise their needs above those of the patient.

> Definitely yeah [I'm not able to bring issues up with the patient], even when I'm not feeling that great...I'm on this motorcycle forum and I've got a lot of…private messages from different people to make sure I'm ok. (C11)

Carers also noted the potential for technology to improve carers' support networks and decrease feelings of isolation in the caring role by linking carers experiencing similar situations.

> When you're in it you'd feel like the only one, so if you had someone else that you could talk to [in a chat room or forum] that'd be really good. (C26)

Carers reported technology provided them with an opportunity to learn about different services and entitlements and to identify local services that may be needed throughout the caring period.

> When we log in, it will identify our location...it [will] come up with all the information to all of the different support units and respite, the aged care team, the palliative care. (past carer focus group)

Personal support requires face-to-face interaction

Carers varied in their agreement about the benefits of technology in meeting their personal support needs. Some carers described that "an app…would be really vital" (C8) in improving access to support.

Other carers reported a lack of desire to engage with digital technologies as they preferred to access support using other methods such as face-to-face settings or lacked confidence when using technology, and, for some carers "I don't have a mobile phone" (C27).

> You would use the things that you've built a relationship with [for support]…a phone is not really a connection. (C34)

Discussion

Carers require a variety of support services to manage their own needs and maintain home life while providing care for someone with cancer [14]. Whether and how carers accessed support was influenced by their perceptions of the severity of their needs, sensitivities associated with prioritising their needs over the needs of the patient, and the adequacy of information available.

The current study highlighted the reluctance of carers to recognise their own needs and prioritise them over the needs of patients and is consistent with previous findings [15]. The need for personal support often resulted in carers' feelings of guilt and burdening others. Guilt can also be experienced by carers who have to work or who experience interruptions to the caring role [16] and may augment carers' beliefs that they should focus only on the needs of the person with cancer, contributing to carers' neglect of their own needs [17]. Carers who have been in the caring role for prolonged periods are more likely to address their own needs [5]. In the current study, carers reported addressing their own needs when they were perceived to be of equal value to the needs of patients and used informal supports for day-to-day tasks; however, these were not appropriate for long-term use.

Lack of awareness of services available to carers often meant that carers were unlikely to access services and this could have an impact on the number or severity of unmet support needs [7, 18].

Carers described how communication barriers with health professionals and patients affected their ability to seek support and again this is consistent with previous research [7, 15]. Interactive health communication tools have shown positive carer and patient attitudes towards using technology to improve communication [19]. Carers perceived receiving stronger support from other carers, who may have better understanding of the caring experience and what to expect from health services. The benefit of peer support is evident as carers can share information, support, and reassurance and it enables carers to normalise the need for support during the caring period [15, 20, 21].

Carers perceived that there was little support available to meet their personal needs in hospitals. This perception may be due to a reduced capacity to provide support by health services facing competing financial demands [22] or that carers were not aware of supports offered. The consequence for carers is the need to actively search for appropriate resources and this may explain why few carers in our study reported using formal support services. Prior knowledge of services has shown to increase usage among carers. A review of an Australian cancer organisation [18] found that only 30% of carers were aware of their existing information and the availability of a support telephone service. Of those who accessed the service, over 70% stated they were likely to use the service again [18].

Carers identified that technology may help improve access to informal and formal supports. Technology has previously been shown to be helpful in improving access to social support among carers of people with varying illness and those looking after children [12]. Technology delivery modes have been described as limited, only providing computer/Internet-based support [23]. Further research is needed, for example to assess the usefulness of advertising support services through online and social media avenues and its impact on carers' awareness and use of services. The suitability of specific technology such as smartphone applications, interactive technology, and social media needs further evaluation within the context of carers of adults with cancer. A better understanding is needed of how technology can be used to link carers to a variety of support services and whether technology is acceptable to carers so that carers who prefer different modes of support delivery have equal opportunity of finding and seeking support. Improving or streamlining services for carers into one technology support system such as a smartphone application may increase their knowledge of support available.

Limitations

The study included carers of a similar geographical location who spoke English and felt comfortable discussing personal support needs. Expanding the sampling frame to include carers from more diverse backgrounds would help validate the findings and inform technological solutions. Background information about carer characteristics and health status was not collected; therefore, the heterogeneity of these results is unknown in the context of existing carer burden.

Conclusion

Carers experience variable needs throughout the cancer trajectory and significant barriers in accessing support services to meet personal needs. Digital technologies may represent an opportunity to overcome these barriers and to effectively support carers throughout the caregiving trajectory. If digital solutions are to be successful however, they need to be targeted to the unique experience of carers during the cancer trajectory.

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Compliance with ethical standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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