Evaluation of an online toolkit for carers of people with a life-limiting illness at the end-of-life: health professionals' perspectives

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Abstract.   Carers of people with a life-limiting illness report unmet information, practical, and emotional support needs, and are often unaware of services available to help improve preparedness, wellbeing, and reduce strain. CarerHelp is the first e-health toolkit that focuses on the information and support needs of carers of people with a life-limiting illness at the end-of-life, using a pathway approach. This study investigated the usefulness of CarerHelp, from the perspective of health professionals who care for these people. Through a 10-min online survey, health professionals provided feedback about their user experience and perceived usefulness of the website. Their expert opinion was sought to ascertain whether CarerHelp could increase carers' preparedness and confidence to support the person for whom they are caring and thereby improve carers' own psychological wellbeing. Health professionals also evaluated whether CarerHelp adequately raised awareness of support services available. CarerHelp was perceived as a useful resource for increasing preparedness for the caring role, including physical tasks and emotional support. Health professionals reported that CarerHelp would increase carers' knowledge of services, confidence to care and ability for self-care. Health professionals endorsed CarerHelp as a useful information source, guide for support, and would promote CarerHelp to clients and their families.

Keywords: carer strain, palliative care, home death, e-health, end of life, carers, terminally ill, e-resource.

Introduction

National standards for palliative care in Australia mandate that family carers of people with life-limiting illness receive sufficient information to support them in their role (Palliative Care Australia 2018a). A life-limiting illness is defined as an illness where it is expected that death will be a direct consequence (Palliative Care Australia 2018b). Carers report the need for disease-specific information relating to diagnosis, prognosis and treatment (Aoun *et al.* 2013; Arias Rojas and García-Vivar 2015), and information and support relating to patient care needs (e.g. assistance with symptom and medication management, dressing, showering, transport to and from appointments) (Aoun *et al.* 2013), practical support with household tasks (e.g. making meals) (Aoun *et al.* 2013), and self-care and coping (Arias Rojas and García-Vivar 2015; Barker *et al.* 2017). Currently, carers have access to some good-quality, disease-specific information,

or general carer information, such as that available on Carer-Gateway (Australian Government Department of Social Services 2020). However, ready availability of relevant information specific to palliative care or end-of-life care may be lacking (Morris *et al.* 2015). End-of-life is defined as 'the period when a person is living with and impaired by a fatal condition even if trajectory is ambiguous or unknown' (Australian Commission on Safety and Quality in Health Care 2017). In addition to the various information needs reported by carers, carers also report the need for better access to support post-discharge (Arias Rojas and García-Vivar 2015), support navigating the healthcare system (Doherty *et al.* 2016), and the need for continued support and follow up after death (Funk *et al.* 2010; Harris *et al.* 2018). Being better prepared for the caring role and for death are commonly reported as unmet needs for carers of people with life-limiting illness at the end-of-life (Barker *et al.* 2017).

This study involved the development and evaluation of an online toolkit for family carers looking after someone with a life-limiting illness. The online toolkit is called CarerHelp (CarerHelp Project Team 2020). CarerHelp provides essential information on how to provide care to a partner, family member, or friend with a life-limiting illness at the end-of-life. CarerHelp is the first Australian evidence-based e-health toolkit that focuses on the information and support needs of carers of people with a life-limiting illness requiring palliative care.

CarerHelp aims to better prepare carers to support their friend/relative/partner, promote awareness of available support services, and enhance carers' own psychosocial wellbeing. Carers need to be well prepared and supported in order to care for those with a life-limiting illness at home, which is where most people prefer to be cared for (Foreman *et al.* 2006). The implications for not having adequate support and preparation extend beyond negative outcomes for the patient. Carers need to be well supported as they are more prone to physical and psychological morbidity; tend to be elderly; are responsible for numerous tasks; are financially disadvantaged (Aoun *et al.* 2013; Harris *et al.* 2018), are socially isolated (Harris *et al.* 2018), are not aware of available support; have needs equal to those of patients; have limited prior exposure to death and dying; and feel excluded from information and care planning (Hudson and Payne 2011; Barker *et al.* 2017).

The development of CarerHelp was informed by a scoping review of carers' needs at the end-of-life, interviews with carers themselves, and guided by a national reference group to ensure carers' information and support needs were addressed by the toolkit. CarerHelp includes information, tools (including a carer preparedness tool), videos and short learning modules that are structured around a pathway approach, recognising that not all carers will need the same information and support or be at the same point in the caring journey (Poppe *et al.* 2020). The five pathways on CarerHelp include: Pathway 1 – When someone needs care; Pathway 2 – Caring when death is a possibility; Pathway 3 – Preparing for dying; Pathway 4 – When the person is dying; and Pathway 5 – After caring. Each pathway contains resources, information and links to various support services tailored to that stage of caring. Pathway 2–Pathway 5 also contain learning modules specific to that stage. Carer stories, information, and practical tips delivered by health professionals via video are also available to users. Using this comprehensive approach, CarerHelp not only provides information specific to the circumstances of the carer, but also offers guidance and tools to enhance carers' confidence and preparedness in caring. In summary, CarerHelp provides an online solution that can be accessed by anyone at any time to help equip carers, at any stage of the caring role, with the confidence, support and information necessary to care for a partner/relative/friend with a life-limiting illness at home.

The aim of this paper was to elicit health professionals' perspectives on the potential utility of CarerHelp as an information source and guide for carers of palliative patients at the end-of-life. We aimed to capture the expert opinions of the health professionals who provide care to people with a life-limiting illness and their carers, to understand, from a clinical perspective, whether CarerHelp adequately addressed the information and support needs of their clients. The mixed-methods evaluation of CarerHelp explored the following research questions from the perspective of health professionals:

1. Does an online e-health toolkit (CarerHelp) increase family carers' preparedness and confidence to support their partner/friend/relative with a life-limiting illness and thereby improving the carer's own psychosocial wellbeing?
2. Does an online e-health toolkit raise awareness of family carers of support services available for their partner/friend/relative and themselves and how to access them?

Methods

Study design

This paper presents the evaluation of CarerHelp from surveys of health professionals. More information on the larger evaluation program can be found in the evaluation report of CarerHelp 2020 (Parker and Ivynian 2020).

Recruitment and data collection

CarerHelp was launched on 17 October 2019 with an official launch campaign at Parliament House during National Carers week. As part of this marketing, materials were distributed to individuals who had registered interest in the project via the project website and organisations with the target audiences being both carers of people with a life-limiting illness, carer and consumer groups, as well as the following health professionals: specialist palliative care services, primary care networks, health professionals, specialist palliative care doctors and nurses, general practitioners, primary care nurses and allied health professionals. Upon entry to the CarerHelp website, users that identified as health professionals and indicated interest to participate in an evaluation via a pop-up were sent an email invitation with a survey link to provide feedback on CarerHelp. This linked them to REDCap (secure online survey platform) where an information sheet explaining the purpose and risks in completing the survey was explained. Prior to the survey questions being made available, users were asked to check a box indicating they had read the information sheet and were willing to proceed. Health professionals who indicated interest via the pop-up were sent a follow-up email reminder 2 weeks after the initial survey link was sent. The online survey included Likert Scale questions assessing the perceived usefulness of CarerHelp in preparing carers and increasing their confidence in caring, usefulness of pathways, usefulness of resources, videos and learning modules, and feedback on overall functionality and design of the website. Three open-ended questions were used to ascertain users' perceptions of: (1) the most useful aspects of the website; (2) any missing information; and (3) the most important thing carers need to know, as perceived by health professionals.

Data analysis

Online survey data were analysed using descriptive statistics of frequency counts and percentages using IBM SPSS V.26 (IBM Corporation, Somers, NY, USA). Qualitative content analysis (Hsieh and Shannon 2005) was used to manage open-ended responses using word processing software. Feedback was coded and categorised by one author, to group responses that reflected the same concept.

Ethics approval

Ethics approval was granted by the University of Technology Sydney Human Research Ethics Committee in October 2019 (ETH19–4049).

Results

Participant characteristics

Of the 56 health professionals contacted, 18 returned feedback surveys (32% response rate). Not all participants answered all questions (50% of cases had missing data). For this reason, entire cases were not excluded, and instead variables with missing data have been marked in each table, and frequencies have been reported out of the total number of responses for each item. As shown in Table 1, most participants were registered nurses (44%) working in specialist palliative care services (41%). Palliative patients/carers were the primary patient/carer group for >70% of participants (71%).

Preparing carers and increasing confidence in caring

Overall, CarerHelp was rated very useful for increasing carer preparedness by almost half of participants (8/17), and very useful for increasing preparedness for physical and emotional care needs by 6/17 and 10/17 participants respectively (Table 2). CarerHelp was perceived as very useful to increase knowledge of services by 7/17 participants, very useful to increase confidence to care by 5/16 participants, and very useful to increase ability to self-care by 8/16 participants (Table 2). All other participants rated each item somewhat useful or pretty useful (Table 2).

Pathways and overall website feedback

All participants thought the five pathways was a useful way to structure the website for carers. Of the 18 participants, 13 viewed pathway 1 and pathway 2, 15 viewed pathway 3, 15 viewed pathway 4, and 17 viewed pathway 5, making it the most popular. All pathways were rated from 'somewhat' to 'very' useful.

All participants (*n* = 18) reported that they would refer patients/carers and colleagues to CarerHelp. Table 3 illustrates overall feedback on CarerHelp, including perceived ease of navigation and appropriateness of language (easy-to-read and understand).

Table 1. Participant characteristics (*N* = 18)

Characteristic	*n* (%)
Position (*n* = 16)	
Registered nurse	7 (44)
Care worker/assistant in nursing	2 (13)
Allied health practitioner	4 (25)
General practitioner	1 (6)
Other	2 (13)
Work setting (*n* = 17)	
Hospital	2 (12)
Community nursing	1 (6)
Commonwealth Home Support Program	2 (12)
Home care	1 (6)
Respite care	1 (6)
Specialist palliative care services	7 (41)
Other specialist services	1 (6)
Other	2 (12)
Work involves looking after patients with a life-limiting illness or supporting their carers (*n* = 17)	
Yes, primary patient/carer group	12 (71)
Yes, but not primary patient/carer group	3 (18)
No	2 (12)

Table 2. Carer's preparedness and confidence in caring

	Not at all useful	Not very useful	Somewhat useful	Pretty useful	Very useful
Overall, how useful is CarerHelp for increasing family carers' preparation for caring? (*n* = 17)			4/17	5/17	8/17
How useful is CarerHelp for increasing family carers' preparation for undertaking physical care needs? (*n* = 17)			4/17	7/17	6/17
How useful is CarerHelp for increasing family carers' preparation for fulfilling emotional care needs? (*n* = 17)			2/17	5/17	10/17
How useful is CarerHelp for increasing family carers' knowledge about services? (*n* = 17)			2/17	8/17	7/17
Overall, how useful is CarerHelp for increasing family carers' confidence to care? (*n* = 16)			2/16	9/16	5/16
Overall, how useful CarerHelp for increasing family carers' ability to care for themselves? (*n* = 16)			2/16	6/16	8/16

Table 3. Feedback on CarerHelp overall

	Not at all	Only a little bit	Somewhat	Very	Extremely
Overall, how helpful did you find the website? (*n* = 17)			1/17	7/17	9/17
Overall, how helpful do you think this website will be for patients/family carers? (*n* = 16)				9/16	9/16
Overall, how easy to read and understand was the information provided on the website? (*n* = 18)			2/18	8/18	8/18
Overall, how easy to navigate was the information provided on the website? (*n* = 18)			4/18	10/18	4/18

Table 4.   **Perceived usefulness of tools**

	Did not use	Not at all useful	Not very useful	Somewhat useful	Pretty useful	Very useful
Self-care plan ($n = 17$)	3/17			1/17	5/17	8/17
Are you prepared for caring? (carer check) ($n = 18$)	3/18				5/18	9/18
Is caring at home an option? ($n = 16$)	3/16			1/16	4/16	8/16
After-caring resource (checklist for moving forward) ($n = 16$)	3/16			1/16	5/16	7/16

Table 5.   **Perceived usefulness of learning modules**

	Did not view	Not at all useful	Not very useful	Somewhat useful	Pretty useful	Very useful
Caring when death is a possibility ($n = 15$)	4/15				5/15	6/15
Being prepared for the changes ($n = 15$)	4/15				4/15	7/15
Managing symptoms ($n = 15$)	4/15				3/15	8/15
After caring ($n = 17$)	4/17				3/17	10/17

Website feedback: usefulness of tools and videos

Participants were also asked to rate the usefulness of various tools available in the carer library. For those who viewed the tools, they were rated from 'somewhat' to 'very' useful Table 4.

Participants were asked to rate the usefulness of videos from 'not-at-all useful' to 'very useful'. Not all participants viewed each of the videos, but users who did rated them as 'pretty useful' or 'very useful'.

Website feedback: usefulness of learning modules

Participants were asked to rate the usefulness of each of the four learning modules available. Not all participants viewed each module; however, those that did rated them as 'pretty useful' or 'very useful' (Table 5).

Open-ended feedback

Most useful aspect of the website

Having relevant, easy-to-understand information that was presented clearly in one place was noted as the most useful thing about the website. The printable resources, learning modules and videos were also noted as important features of the website. Recognising that everyone grieves differently, practical and honest tips and reassurance for carers were also highlighted as important features.

Missing information

Responses included the needs for state-specific information, information on mouth care, and who to notify when a person dies. One participant noted that although nothing was missing, resources may need to be updated as supporting roles evolve (e.g. end-of-life doulas). The need to update contact links regularly was also mentioned. One participant described confusion regarding the 'contact us' link, expecting to see a direct link to support rather than information about the website.

The one most important thing carers need to know

Responses indicated that knowing what the future might look like and what to expect when someone is dying were important.

Other practical tips including care requirements, recording symptoms, who to contact, and who to notify after death, were also noted as the most important things carers need to know. Several participants said that being aware of the support that is available to carers, where and how to access this support, and understanding that they are not alone was the most important thing. The importance of carers looking after themselves to sustain the caring role was also highlighted. Finally, being comfortable with asking for help and not seeing it as a failure was raised as important.

Discussion

These results indicate that CarerHelp is a useful resource, from the perspective of health professionals. Although only a proxy rating for family carers, health professionals all rated CarerHelp as useful in increasing family carer preparation for the caring role, including undertaking physical tasks and providing emotional support. In addition, they rated that CarerHelp would increase family carers' knowledge of services, their confidence to care and ability for self-care.

Family carers provide the majority of care at home in the last year of life (Ward-Griffin and McKeever 2000) and are thus essential for supporting home death (Gomes and Higginson 2006). Carers' tasks include physical care of the patient, medication and symptom management, household and daily activities, and providing emotional support (Aoun *et al.* 2013; Arias Rojas and García-Vivar 2015; Barker *et al.* 2017; Harris *et al.* 2018). Results showed that all health professionals felt CarerHelp was a useful tool to increase carers' preparedness for attending to physical and emotional care needs of the patient. This is a promising result, as it is commonly reported that carers feel unprepared for the caring role and feel they lack adequate knowledge and ability to care (Boyd *et al.* 2004). According to health professionals' expert opinion, CarerHelp can help address this need and make carers feel more adequately prepared for not only the practical aspects of the caring role, but also the emotional care needs of the patient. The carer check tool (Are you prepared for caring?) is an eight-item questionnaire

available on CarerHelp and could easily be distributed across various carer networks to enhance carer preparedness.

The physical, financial and emotional impact of caring at home at the end-of-life is well documented in the literature. The demanding nature of the caring role and the negative emotions associated with watching a loved one suffer and deteriorate contributes to immense emotional and psychological difficulties, financial strain, occupational disruption, activity restrictions, social dysfunction and relationship challenges (Funk *et al.* 2010). Health professionals perceived CarerHelp as a very useful tool to increase carers' ability to care for themselves at a time when self-care is often neglected. CarerHelp includes a self-care plan, dedicated to ensure carers consider and manage their own wellbeing as well as the care of the recipient.

The unique pathway structure of the website was perceived as useful by all health professionals. CarerHelp provides evidence-based information to meet the needs of carers at any stage of end-of-life care, to help them feel more prepared for the caring role and for the decline and death of the patient. Carer stress, anxiety and negative emotions are compounded by not knowing what to do and how to get support (Funk *et al.* 2010). Studies have shown that lack of support from formal services worsens feelings of unpreparedness (Terry *et al.* 2006). Evidence also suggests that carers are not inclined to use the services that are available to them, including use of bereavement services (Cherlin *et al.* 2007). Despite this, carers report the need for support and follow up after death (Funk *et al.* 2010; Harris *et al.* 2018) to manage the painful emotions that continue after the caring activities stop (Grbich *et al.* 2001). Not only is CarerHelp useful for information provision, but also raises awareness of support services available specific to the needs of the carer throughout the caring trajectory. For example, resources and links provided in Pathway 5 are all specifically dedicated to the after-caring stage. The need to regularly update support links to ensure the website remains relevant and that carers are able to contact the support they need at any given stage is an important consideration for this e-health toolkit.

Carers report the need to maintain a sense of a 'normal life' (Funk *et al.* 2010) by finding time for leisure activities and self-care (Beattie and Lebel 2011), and maintaining social relationships (Bergin and Mockford 2016). The 'carer voice' section of CarerHelp helps to normalise the caring experience, including videos detailing the impact of caring on daily life and considerations that were made throughout the journey in a variety of caring situations. One of the most useful aspects of the website was recognition of the unique experience of grief, highlighting the importance of representing a variety of carer experiences to help carers feel supported and understood regardless of circumstance.

In summary, CarerHelp is an evidence-based accessible online resource for carers of someone with a life-limiting illness, a person with a life-limiting illness and health professionals supporting these individuals. CarerHelp offers content in formats that are valued (i.e. videos, learning modules) through a digital platform, enabling easy access to information when needed. Furthermore, the online format of CarerHelp facilitates capacity to build awareness of the role of carers and services available to them. Although not the focus of the current study, the effectiveness of CarerHelp to support individuals with life-limiting illnesses could be investigated as one component of a multicomponent intervention or individually as an education intervention for carers of people with a life-limiting illness.

Limitations

This evaluation presents perspectives of a small group of health professionals on the utility of CarerHelp, providing a proxy rating only for carers and care recipients. This sample of health professionals providing feedback was small, limiting generalisability of results. Perspectives of carers of people living with a life-limiting illness, and/or people living with a life-limiting illness were not directly represented, so the usefulness of CarerHelp was not verified by either group.

Conclusion

This study suggests that expert health professionals view a new online resource – CarerHelp – as a useful resource to increase carer preparedness and confidence in caring for someone with a life-limiting illness. A larger sample size and verification from carers is required to confirm the utility of CarerHelp. CarerHelp is designed to provide a novel pathway approach to provision of information ensuring carers can access information tailored to their particular circumstances. Increasing carer preparedness and confidence is one strategy to increase the possibility that end-of-life care at home can be provided for those with a life-limiting illness.

Conflicts of interest

The authors declare no conflicts of interest.

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