Development of a smartphone application for informal carers of people with cancer:
processes and learnings

Natalie Heynsbergh¹, Leila Heckel¹, Mari Botti², Eric (Seung Chul). O³ and Patricia M. Livingston⁴

¹Deakin University, Geelong, Faculty of Health, School of Nursing and Midwifery, Victoria 3220, Australia;
²Deakin University, Geelong, Faculty of Health, School of Nursing and Midwifery and Epworth HealthCare, Victoria 3220, Australia;
³Deakin University, Geelong, Faculty of Health, School of Psychology, Victoria 3220, Australia;
⁴Deakin University, Geelong, Faculty of Health, Victoria 3220, Australia.

¹Correspondence to: Ms Natalie Heynsbergh, Deakin University, Geelong, Faculty of Health, School of Nursing and Midwifery, Victoria 3220, Australia. E-mail: nheynsb@deakin.edu.au.
Abstract:

Background There are few support systems available to informal carers who provide care to cancer patients. Smartphone applications have the capacity to reach large audiences and can provide information and support at a time convenient to carers.

Objective To describe the process of developing and designing a smartphone application prototype for carers of adults with cancer involving focus groups and interviews with present and past carers, to understand their information and supportive care needs. Carers’ willingness to use a smartphone application as part of an information and support mechanism was also explored.

Methods Carers were recruited from a public hospital, a private hospital and a carer organisation and participated in either a focus group or phone interview. Carers answered questions about: their caregiving experience, supportive care needs and items to include in an application to address needs identified. Based on carers’ feedback a smartphone app was designed and tested.

Beta testing was conducted using a convenience sample of participants who completed scenarios to inform the application’s design, functionality and usability. Scenarios were timed and marked as complete or incomplete. Participants completed a questionnaire about the useability of the app. Beta testing occurred in two stages: a paper-based version of the app and an app-based test using participants’ preferred device. Alpha testing was completed internally to ensure the functionality of the app.

Results 33 carers participated in phone interviews and 12 in focus groups, their average age was 55 (SD 14) and 60% were female. Carers noted that smartphone technology may improve their ability to seek information and support in managing their own health as well as the care needs of the person with cancer. Carers requested a variety of resources
including information, support services and features such as reminders, notepads and calendars.

Paper-based testing: Participants were aged <30 (30%), 30-49 (30%) and 50+ (40%) and 60% were male. Participants found the app user-friendly and pleasing in appearance. Navigation was unclear within three of the headings. Headings and contents were reorganised to improve useability.

App-based testing: Participants were aged <30 (20%), 30-49 (30%) and 50+ (50%) and 50% were male. Participants reported the app user-friendly and easy to navigate. The majority (60%) of participants were unable to create a shortcut icon to add the app to the home screen of their phone. Video instructions were created to assist with downloading and navigation for those with less confidence in using apps. Google Analytics was modified to provide accurate usage data.

**Conclusion** Carers require information and support during the caring period. The Carer Guide Application was created to assist them during their time of caring. Further testing is required to assess how carers will receive and use the app on a day-to-day basis.

**Keywords:** cancer, carer, smartphone, app, technology.
Introduction

Cancer is a significant issue worldwide with over 14 million people diagnosed in 2012 [1]. Globally US$1.16 trillion are spent on cancer every year [1]. The financial burden on healthcare systems has resulted in quicker discharge times for patients and increased the need for care to continue in the community [2]. In Australia, there are approximately 2.7 million informal carers who are not paid for the care they provide [3]. Informal carers are often family members who may have limited awareness and understanding about the disease to sufficiently meet the care needs of individuals [4]. As a result, physical, mental, social and financial burdens are common among carers resulting in negative health outcomes and poor wellbeing [5].

Carers often neglect their own needs while looking after someone with cancer [6, 7]. Face-to-face support through local medical and counselling services can be costly, time consuming and inaccessible to carers who are unable to leave care recipients alone or live in remote areas [8]. Technology may provide a solution in addressing the needs of many carers. Technology-based tools allow large audiences to have access to information and support networks when addressing specific health needs [9, 10] [Australian Communications and Media Authority, 2015 #206; Australian Communications and Media Authority, 2015 #1284]. Smartphone applications (apps) allow individuals to access information and support at a suitable time when needed and in the privacy and comfort of their own home [8, 10]. Recent trends have shown increasing availability of 4G internet connection worldwide [11] and by 2020, 70% of the population are expected to own smartphones [12]. While these figures suggest that smartphone and roaming internet access is common, individuals use technology in varying ways, therefore it is important to assess carers’ attitudes towards digital technology as a supportive tool. Existing cancer information and support helplines
are not widely recognised or used among people affected by cancer and carers only account for approximately 20% of people who initiate contact [13, 14]. While web-based interventions have been found to be appropriate for use among carers and are accessible to a larger number of people [15], they are not always available through smart devices, and this can limit carers’ ability to access support in times of need [16]. Previous studies have shown positive results for the use of smartphone apps across different circumstances including self-management of cancer [17, 18], for carers of paediatric illness [19-21]. However, there have been no studies assessing the use of smartphone apps among adult carers providing care to another adult with cancer [15].

The aim of this paper was to describe the process of developing a smartphone app for carers of adults with cancer. A pilot study is currently being conducted to test the feasibility, useability and acceptability of the app described in this paper in a sample of informal carers caring for an adult with colorectal cancer.

Methods

Study design

This study comprised a multiple methods design to inform development of the app and included three sequential phases: 1) focus groups and phone interviews with present and past adult carers to assess their information and supportive care needs as well as their attitudes towards smartphone technology, including existing barriers affecting technology uptake; 2) smartphone application design, content development, and app programming; and 3) alpha and beta testing, and user testing of the application. Findings from Phase 1 informed the design of the app and its content.
The study was guided by the use of two theoretical frameworks. The Theory of Planned Behaviour (TPB) and the Unified Theory of Acceptance and Use of Technology (UTAUT). The TPB was used to investigate the influence of beliefs and attitudes towards a range of social and personal behaviours [22]. In this study these concepts of behavioural beliefs, normative beliefs and control beliefs were applied to the use of technology for gaining and understanding health information.

UTAUT was incorporated to measure the concept ‘facilitating conditions’. These refer to external factors contributing to technology use such as the ownership of a smartphone device and internet connectivity [23]. The TPB and UTAUT were used to assess carers’ motivation to use a smartphone app.

**Phase 1: Focus groups and phone interviews**

To develop a smartphone app that was responsive to carers and specific to their needs, focus groups and phone interviews were conducted with current and past adult carers looking after another adult with cancer. Questions explored the attitudes, behaviours, social pressures and facilitation conditions affecting smartphone app use, and the content desired in a smartphone app to address carers’ needs. Recruitment continued until saturation of data occurred; a total of 45 carers were recruited (12 into focus groups and 33 phone interviews).

**Phase 2: Design, content development, and programming of the app**

The smartphone application, referred to as the Carer Guide App, was designed to be used by carers of people with cancer based on Shneiderman’s “Eight Golden Rules of
Interface Design”. The content and high-level user experience were informed by the findings of Phase 1 of the project. The Carer Guide App was designed and developed by e-Resource developers at Deakin University and built using a hybrid web-based structure, incorporating technologies including: HTML 5, CSS 3, JavaScript, JQuery, Ajax, PHP and MySQL. Email notifications to users were triggered by a time-based scheduler (known as a cron job) in a Unix-like computer operating system. A hybrid web-based structure was chosen over that of a native app as it significantly reduced time required in the development stage of the project, including programming, updating functionality and content revision. Further, the structure that was chosen did not require distribution through either the App Store or Google Play. This saved time in deployment as the often lengthy review processes of those distribution channels were bypassed. The chosen structure allowed for development of the app which was accessible on a wider range of devices. The app was accessed at a URL address through any current generation mainstream internet browser. The app contained both static and dynamic content, accessible through a primarily iconised navigation system. The text in the app contained links to both external websites and built-in interactive functionality to maximise user experience. Security of sensitive information provided by users was a priority, enhanced by features such as personalised secure logins and encrypted data. Figure 1. outlines the stages of the app development process.

Figure 1.Development stages of the Carer Guide App
Phase 3: Testing of the application

Paper based User Acceptance Test (UAT)

A convenience sample of 10 adults were recruited to test a paper-based version of the Carer Guide App. This was achieved using printed screen shots of the app. Figure 2 presents an example of screen shots used, screen one was the login page, screen two the main menu, and screen three the relevant information.

During the UAT, participants were asked to complete scenarios in which they had to navigate the app to locate information, for example: “You require information about financial aid, where would you go to learn about benefits you are entitled to?” Participants also completed a questionnaire including information about: their gender, age, confidence in using apps, usability of the app and comments for improvement.

Figure 2. Screen shots of the Carer Guide used in the paper based user test.
Alpha and beta testing

The Carer Guide App underwent several rounds of internal testing known as alpha and beta testing [24]. Alpha testing was used to assess the input and output of the functions of the app and was performed while building the structure of the app [24]. Beta testing assessed the complete function and applicability of the app using a smartphone interface among test participants [24]. Google Analytics was linked to the Carer Guide App to collect usage information on: the number and length of sessions, device used and frequency of pages visited from each participant.

App based user testing (UX test)

A second convenience sample of 10 adults were recruited to test the first prototype version of the Carer Guide App.

Test participants were asked to complete scenarios in which they had to download the app, create a shortcut icon, log into the app, navigate to locate information, access hyperlinks, phone numbers, and navigate through website browsers. Participants also completed a questionnaire including information about: their gender, age, confidence in using apps, functionality of the app and comments for improvement.

Results

Focus groups and phone interviews

Overall, 38 (85%) carers reported a positive attitude towards using apps and the concept of developing an app for carers and were confident with using smartphones. Lower
confidence was expressed by infrequent and non-users who identified the need for brief instructions prior to use to increase confidence levels.

A range of social pressures impacting on app usage were identified. The majority of carers (76%) reported responding to recommendations from healthcare professionals, social networks (21%), anyone (9%), cancer organisations (9%), others in the same situation (6%) and app store listings (3%). Some carers responded to more than one recommendation. Three carers (9%) would not be influenced by others to use an app and were more likely to prefer using the computer or talking face-to-face with a healthcare professional. Potential barriers affecting the use of smartphone apps included not owning a smartphone, not using apps and not having adequate internet connectivity to access apps from home.

Carers provided varied ideas for content that could be included in the app. Overall carers reported a need for more cancer-related information, links to support services and social networks, case studies, interventions to manage symptoms at home, information on how to identify serious side effects and when to escalate care, on hospital-specific navigation, and resources to manage their own needs. Resources mentioned included: calendar with symptom tracking, reminders for appointments and medications, notepad, contacts, a search function and the ability to synchronise the app with other phone functions. Carers specified that the app should have information specific to their needs and the use of push notifications was regarded as beneficial because the app would be perceived as less impersonal.

**Design, content and technical development**

Results from Phase 1 indicated that carers required the app to be specific to their information and support needs. To accommodate this within the project timeline the app
content was developed specifically to support carers of people with colorectal cancer. Colorectal cancer was chosen as it has a high prevalence in Australia and increased the likelihood of recruitment of both female and male carers [25]. The Carer Guide App took three months to develop including user testing and alpha and beta testing.

Initial development decisions included: app name, colour scheme, logo and icon pictures and layout structure. To ease navigation similar content materials were grouped together under one main category, this is shown in Figure 3.
Figure 3. Initial structure of the Carer Guide App

Testing of the Carer Guide App

**UAT**

The sample of 10 comprised past carers, non-carers and a medical professional on an oncology ward. Participants’ age ranged from <30 (30%), 30-49 (30%) and 50+ (40%) and 60% were male.
Participants rated their perceived level of confidence in using apps as very confident (60%), moderately confident (30%) and novice (10%).

Overall the appearance and layout of the Carer Guide App were considered favourable, however there was some confusion between two icons, Lifestyle and Wellbeing. Of the 16 tasks, 13 were completed successfully by 100% of participants. The three tasks not completed by all participants included: finding financial aid (60% completed), seeking counselling sessions (90% completed) and seeking peer support (90% completed). These three topics related to the app icons Lifestyle, Wellbeing and Social. Five scenarios took participants on average greater than 20 seconds to complete, this included: finding financial aid (66.5 seconds), counselling sessions (36.8 seconds), seeking peer support (26.1 seconds), finding carer resources (29.7 seconds) and saving and exiting the notepad (26 seconds).

Overall the Carer Guide App’s features and functionalities were satisfied by the testing group. Out of a score of five participants found the app was easy to navigate and visually appealing (5 out of 5). The icon pictures were also relevant to information on the individual pages. Participants were asked for suggestions to make the app more user-friendly, participants suggested changing the iconised navigation titles, rearranging the layout of contents and having the capabilities to synchronise app contents with other phone functions.

The following UAT changes were incorporated to improve the appearance and useability of the Carer Guide App.

1. The icons ‘Lifestyle’ and ‘Wellbeing’ were merged. Icon name: ‘Wellbeing’. Icon picture: smiley face. Icon contents: physical wellbeing, diet and nutrition, counselling and mindfulness activities.
2. A separate financial aid icon was created. **Icon name:** 'Financial and legal'. **Icon picture:** dollar symbol.

3. The icon 'Social' was renamed to specify that it relates more to connecting with others rather than social issues e.g. social work. **Icon name:** 'My social network'.

4. The Icon ‘Contact/quick references’ was renamed to reduce ambiguity. **Icon name:** ‘Contacts’.

Following the UAT, the layout of the main menu and sub menus were modified and are displayed in Figure 4. Submenu one and two were condensed after consultation with the app developer to reduce the number of screens participants would have to search through to find the information required. During this process Medical Terminology was included in both the main menu and the Cancer Information sub-menu. This was done as the content was relevant for inclusion in Cancer Information, but due to the volume of information in this section, may have required additional time to access. To enhance useability Medical Terminology was included in the main menu of the Carer Guide App for quick reference use.
<table>
<thead>
<tr>
<th>Main menu</th>
<th>Sub menu/information screen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer information</td>
<td>What is colorectal cancer?</td>
</tr>
<tr>
<td></td>
<td>Survival and cancer trends</td>
</tr>
<tr>
<td></td>
<td>Treatment plan</td>
</tr>
<tr>
<td></td>
<td>Side effects</td>
</tr>
<tr>
<td></td>
<td>Practical aspects of cancer</td>
</tr>
<tr>
<td></td>
<td>Medical terminology</td>
</tr>
<tr>
<td></td>
<td>Daily management</td>
</tr>
<tr>
<td></td>
<td>Stoma care</td>
</tr>
<tr>
<td></td>
<td>Diet and nutrition</td>
</tr>
<tr>
<td></td>
<td>When to go to hospital</td>
</tr>
<tr>
<td>Carer information</td>
<td>Mindfulness</td>
</tr>
<tr>
<td></td>
<td>Where to get support.</td>
</tr>
<tr>
<td></td>
<td>Counselling</td>
</tr>
<tr>
<td></td>
<td>Exercise</td>
</tr>
<tr>
<td></td>
<td>Diet and nutrition</td>
</tr>
<tr>
<td></td>
<td>Physical wellbeing</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>Phone contact</td>
</tr>
<tr>
<td></td>
<td>Face-to-face social groups</td>
</tr>
<tr>
<td></td>
<td>Facebook</td>
</tr>
<tr>
<td>Financial aid</td>
<td>Financial assistance for carers</td>
</tr>
<tr>
<td></td>
<td>Financial assistance with stoma care</td>
</tr>
<tr>
<td></td>
<td>Legal assistance</td>
</tr>
<tr>
<td>Hospital Information</td>
<td>Hospital A</td>
</tr>
<tr>
<td></td>
<td>Hospital B</td>
</tr>
<tr>
<td></td>
<td>Hospital C</td>
</tr>
<tr>
<td></td>
<td>Hospital D</td>
</tr>
<tr>
<td></td>
<td>Hospital E</td>
</tr>
<tr>
<td>Contacts</td>
<td></td>
</tr>
<tr>
<td>Notepad</td>
<td></td>
</tr>
<tr>
<td>Medical terminology</td>
<td></td>
</tr>
</tbody>
</table>

Figure 4. Modified structure of the Carer Guide App

**UX test**

An equal number of females (n=5) and males (n=5) tested the app. Participants were:

younger than 30 (30%), 30-49 (20%) and 50+ (50%). The sample included past carers and
non-carers. Android operating systems were used by 30% of people and iOS was used by 70%.

Participants rated their perceived skill in using apps as moderately confident (50%) and extremely confident (50%).

Of the 23 tasks, 18 were completed by 100% of participants. Completion rates for the following five tasks were lower: creating a shortcut icon (40% completed), finding peer support (90% completed), adding a new contact (90% completed), returning to the Carer Guide App window after visiting an external website (90% completed), and clicking on an external number to make a call (90% completed). Four of these tasks related to system factors and one related to misunderstanding of content.

On average, participants completed the majority of tasks (18 out of 23 tasks) in under 20 seconds. Five tasks took participants on average greater than 20 seconds to complete, this included: downloading the app (31.8 seconds), creating shortcut icon (23 seconds), finding symptom management (46.5 seconds), finding benefits and payments (20.7 seconds) and seeking peer support groups (29.3 seconds).

Participants rated the app as easy to use and the phone numbers were clear and easy to recognise and access (4.7 out of 5 for each aspect). Ease of accessing the app after visiting an external website was scored 4.1 out of 5. The highest useability factors of the app were awareness of external website links and ease of accessing external links; these scored 4.9 out of 5 and corresponding tasks were completed by 100% of participants. Ease of creating a shortcut icon was the lowest scoring aspect (3.6 out of 5), as most participants (60%) were unable to complete this task. Of the six participants who could not create the app icon shortcut, two still rated it 3 out of 5 as they stated it was easy to do once shown.
The Carer Guide App was tested on both Android and iOS devices to assess any variation in the performance of the app. During testing it was noted that there were differences between the operating systems. On Android devices problems encountered included not being able to find the shortcut icon once created, Internet and phone links not connecting to external sites or numbers and the ‘Add’ button in the contact menu did not appear. On iOS devices icon pictures were enlarged and pictures appeared in incorrect menus. These errors were not present among all iOS versions. Android errors occurred for two participants and iOS errors occurred for one participant.

Comments for improvement included instructions to create a shortcut icon and improvements in system factors e.g. working links and phone numbers. Individual participants requested changes to iconised navigation titles, layout such as having items in menu format and the ability to synchronise app features to phone features.

Based on these test results the following steps were taken to improve the Carer Guide App:

1. Confirm all links, pictures and buttons are correct and working in all operating systems
2. Inclusion of instructional downloading and navigation videos for both iOS and Android operating systems, comprising information on how to create the shortcut icon, how to navigate between different browsers, how to close browsers, highlight web links and phone numbers and how to use them.

Discussion

Principal results

Caring for someone with cancer can be stressful, and information and support are not easily available [26, 27]. The Carer Guide App was developed to support carers while
they are caring for someone with cancer. Carers may be reluctant to communicate their own needs and struggle to find information that is specific to their own situation [28]. The Carer Guide App provides a means for carers to access information and support anywhere within their Internet connection capabilities and allows carers privacy in addressing their needs [8].

Involving carers in the creation of the Carer Guide App enabled the contents to be designed specifically for carers’ needs. The sample was a heterogeneous group, with participants caring for people with different types of cancer, of different ages and various stages of caring including new, ongoing, recurrent or past carers. This allowed the Carer Guide App to be designed to address the needs of carers from a variety of clinical, demographic and social perspectives. During user testing, inclusion of non-carers was important as not all people have previous experience with cancer prior to becoming a carer. This allowed the Carer Guide App to be tested among people with no prior knowledge of how to address cancer related needs. Both the UAT and the UX testing showed that participants found the appearance of the Carer Guide App favourable. Issues with navigation during the UAT were amended and participants in the UX test were more easily able to navigate the Carer Guide App. Results from the UX test highlighted the need for specific instructions to accompany the Carer Guide App. Tying in with the theoretical frameworks the Carer Guide App was used successfully among people with varying levels of confidence. Feedback during Phases 1 and 3 demonstrated participants’ positive attitudes towards the development of the Carer Guide App. Factors potentially affecting Carer Guide App usage included recommendations from healthcare professionals to use the app. The influence of healthcare professionals on carers information seeking behaviour is consistent with findings from previous research [29-31] and highlights the need to involve staff working in oncology.
settings in the implementation process for new interventions or services. Barriers to using apps included not having access to a smartphone or the Internet.

**Challenges encountered**
While participants were engaged during the development of the Carer Guide App, it was not possible to meet the requests of all carers. For example, requests to include interactive features may impact on overall usability for carers who may be less confident in using apps. As a result, interactive features such as discussion boards and symptoms trackers were not created in this version of the app and synchronising features were not included in the app.

A second challenge was creating the app within the time frame of the research project. The Carer Guide App was developed as a web-based app. While web-based apps are quicker to develop and launch and easier to modify, it required a different approach to downloading the app. Using the web-based app, participants were required to create a shortcut icon and navigate through browser windows when external links are accessed from the Carer Guide App. These factors required testing during the UX test to assess whether participants could understand and navigate these factors and identified the need to develop video instructions for carers to assist them in completing these tasks. However, development of a web-based app allowed for secondary analyses to occur to assess which devices carers used on the Carer Guide App, for example, a phone, tablet, or computer; this may allow for an in-depth analysis about the applicability and acceptance of smartphone apps among carers.

**Strengths of the study**
To the researchers’ knowledge, this app is the first of its kind as carers guided its development, including the content, visual presentation and layout. This research used a co-design process involving carers at each phase of development. This approach may be useful
for future research to guide the development of novel interventions. Another strength of this research was the inclusion of current carers of a variety of cancer types and stages as well as past carers during focus groups and phone interviews. This enabled the content of the app to be created to meet the needs of carers across the illness trajectory.

Limitations

This study has several limitations including the collection of information from carers living in metropolitan areas only, and who spoke English. This may have resulted in the development of an app that is not appropriate for carers living in rural and remote areas or who speak a primary language other than English, as they may experience different needs. The Carer Guide App was not designed to synchronise to other phone functions due to the need to incorporate additional security measures. Not synchronising the Carer Guide App to phone functions decreased the need for security passwords to access the app; this reduced any burden of having to remember passwords in times of stress by recipients.

Recommendations for future research

Future research is needed to assess the applicability of apps for carers living in rural and remote areas and those whose primary language is not English. These groups of people may experience different needs and therefore require other information and services within an app.

Future app prototypes should consider incorporating interactive features such as symptom tracking and calendars as this may be a useful resource for carers. To improve useability across carers of different skill levels or preferences it may be necessary to include the capability to activate or deactivate interactive features within apps. When developing interventions with interactive features or the ability to synchronise to other phone functions
future researchers should consider the development timeframe of their intervention
including the time needed to launch apps through Google Play and the App store.

**Conclusion**
In conclusion, carers require information and support during the caring period. A smartphone app may provide one solution to address these needs. A pilot study is currently underway to test the acceptability and useability of the Carer Guide App.

**Acknowledgements**
This research was supported by scholarships from the School of Nursing and Midwifery, Deakin University, and the Eastern Health Foundation.

**Conflicts of interest**
The authors declare they do not have any conflicts of interest.

**References**


13. Fennell KM, Heckel L, Wilson C, Byrnes M, Livingston PM. How calls from carers, friends and family members of someone affected by cancer differ from those made by people diagnosed with cancer; analysis of 4 years of South Australian Cancer Council Helpline data. Support Care Cancer, 2016. PMID: 26728761
14. Heckel L, Fennell KM, Mohebbi M, Byrnes M, Livingston PM. Demographic characteristics, call details and psychosocial support needs of the family/friends of someone diagnosed with cancer who access Australian Cancer Council telephone information and support services. European Journal of Oncology Nursing, 2017. 28: p. 86-91. PMID: 28478861