# Title: mHealth Intervention for Carers of Individuals with a History of Stroke: Heuristic Evaluation and User Perspectives

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## Abstract

**Background:** Caregiving in stroke is complex, with most carers having little to no preparation to care for individuals with a history of stroke, leading to emotional impact. Technologies such as mHealth can provide the carer with real-time support and prepare the carer to assume their new roles and responsibilities.

**Objectives:** To perform a heuristic evaluation of a mHealth interventions designed to support carers of individuals with a history of stroke and determine the user preferences in stroke caregiving technology to inform future researchers and developers regarding the best practices to support these individuals.

**Methods:** Twenty adults (i.e. ten usability experts and ten carers) participated in an iterative user-centred design study that focused on developing and modifying the mHealth intervention (SeCr) created to support stroke caregiving. The intervention was repeated in four cycles, including two cycles with five usability experts each and five carers each.

**Results:** SeCr was iteratively improved to develop a highly usable product in multiple cycles. Participants demonstrated critical needs in personalized information support, communication with their healthcare needs, and the trust of the user, content, and developer. These critical needs are required to be met to promote long-term acceptance and adherence.

**Conclusions:** While SeCr was developed to address the needs of carers of individuals with a history of stroke, several considerations must be made to ensure it can be used in a real-world setting. Researchers and developers can use co-design or living lab approaches to further meet the needs and expectations of the carer and enables these individuals to be better prepared for stroke caregiving.

**Keywords:** *mHealth, Intervention, Carer, Stroke, Usability, User Experience, Heuristic*

## 1. Introduction

Around the world, more than 80 million individuals have survived one or more stroke(s),[1] which requires acute inpatient care and continued home-based care,[2] generally provided by carers.[3] Unlike other chronic conditions, stroke occurs suddenly, with most carers having little to no time to prepare or adjust to their new roles and responsibilities.[4] As a consequence, over two-thirds of these carers suffer from stress, while approximately 80% experience frustration and anxiety.[5] To reduce the emotional impact of stroke caregiving, researchers have implemented technological support to address the different needs of the carer, including information, therapy, communication and health management. These technologies have demonstrated potential to improve carers health and preparedness outcomes.[6] However, a

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majority of these technologies were developed based on literature studies or past experiences of the researcher, which results in the lack of understanding of the carer's needs, leading to reduced acceptance.[7]

In response to this issue, there is a growing interest in user-centred design principles towards the design of health care technology to improve outcomes, i.e. usability and functionality. The shift towards user-centred design, in the past few years, is evident through the increasing number of iterative and participatory design practices implemented in stroke caregiving.[8-14] However, the extent of its implementation is fairly limited, with a majority of studies failing to describe the rationale of the intervention or its ability to meet users' needs and capabilities.[7] For example, Sureshkumar et al. [11] designed an educational mobile application to support carers of individuals with stroke using user-centred methodology, however, it was developed based on an assumption with no clear assessment of the user requirements and technical capabilities that may lead to issues in the initial design and lack of integration of technology in the everyday lives of the carer.[7] Hence, the approach considered should focus on including target users during the intervention design and implementation to provide a clear understanding of the user needs for an effective intervention to support them in their daily care activities.[15] In this study, a mHealth intervention was developed based on an iterative user-centred design approach to understand the technical needs of the carer and create an intervention that is usable and meaningful in their care activities.

# 2. Methods

## 2.1 Study Design

The study focuses on using an iterative user-centred design (UCD) approach that uses three general principles: (i) early focus on users and tasks, (ii) empirical measurement, and (iii) iterative design.[16, 17] Initially, the authors understood the needs of family carers in their daily care activities based on data collected from literature, social media and surveys, reported and submitted elsewhere.[18] Using a grounded theory approach for interpreting such data,[19] the mHealth intervention was developed and evaluated in a real-world setting as presented in this study.

## 2.2 Intervention

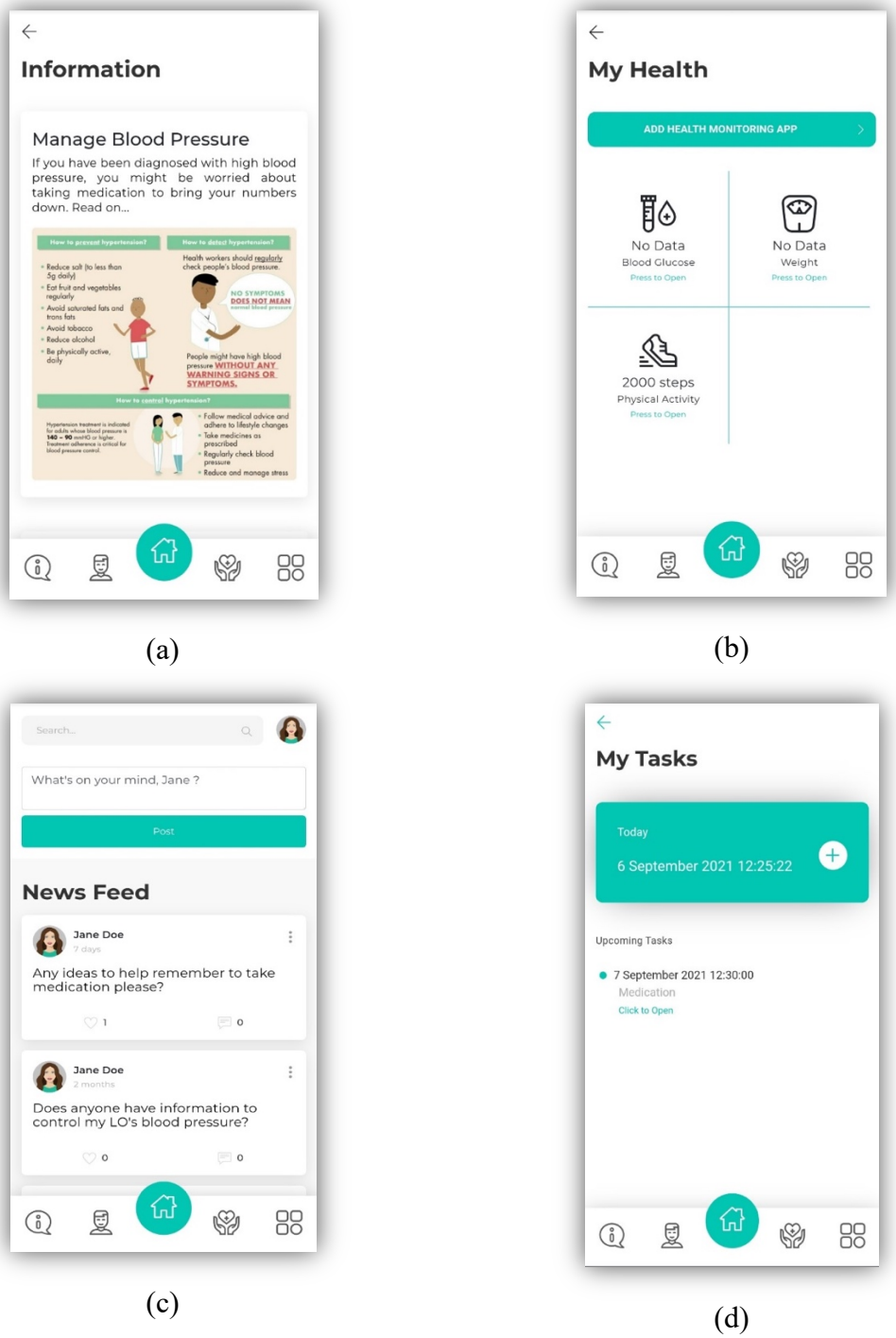
SeCr is a hybrid mobile intervention that provides carers with around the clock information and support. This mobile intervention technology was developed by understanding carers' needs in their daily care activities as described above.[18] This mobile intervention technology prototype consists of four key features: (i) information delivery, (ii) survivor and carer health monitoring, (iii) social communication and (iv) task scheduling and sharing, illustrated in **Figure 1** and as described below:

(i) The **information delivery** feature consists of a personalized recommendation system that uses ontologies consisting of user profiles, activities and interests. The algorithm combines a domain-based inference method and semantic reasoning method, which provides a measure of affinity between the user and the item described by the ontology to provide information more effectively and accurately.

(ii) The **survivor and carer health monitoring** feature consists of tools to monitor health vitals such as blood pressure, blood glucose, physical activity, heart rate and weight. Users have the freedom within this feature to install the app that best suits their needs. The web version of the intervention allowed for manual user data input, while the Android version enabled the connection to numerous off-the-shelf sensors using Bluetooth GATT protocols.

(iii) The **social communication** feature consists of a social media wall such as Facebook or Twitter where the carer could communicate or ask questions to people living with similar experiences.

(iv) The **task scheduling and sharing** feature allows carers to plan for their day using a calendar function within the intervention. Moreover, it enables the primary carer to share tasks with other carers supporting them in their daily care activities.




(a) (b)

(c) (d)

**Figure 1.** SeCr Intervention mobile technology prototype illustrating (a) Information, (b) health monitoring, (c) social communication and (d) task scheduling and sharing features in use.

## 2.3 Participants and Procedure

Two participant groups were included in this study, i.e. Usability Experts and Carers. Usability experts were recruited from Amazon Mechanical Turk between 30th July and 12th August 2021. Amazon Mechanical Turk is a popular crowdsourcing marketplace that enables a large number of people (generally known as 'Turkers') to work on tasks online.[20] On the other hand, Carers were recruited from Carer Organizations in Australia, such as Carers VIC and Carers QLD between 1st July and 1st September 2021. These organizations provide a statewide voice for family carers by representing and providing support in their daily activities. A purposive sampling approach was considered for acquiring a range of variations within the sample, including age, sex, educational qualifications and experience. The inclusion criteria for usability experts were aged 18 years or more with over one year of usability experience, have conducted over 20 similar tasks and can read and write in English. Furthermore, carers were included if they were over the age of 18 years, caring for an individual with a history of stroke in the last five years, and reading and writing in English.

The study employed an iterative testing approach for intervention refinement, which consisted of four cycles. Each cycle included five different participants who performed the following steps: (i) introduction to the mHealth intervention, (ii) participant performs a set of tasks and (iii) intervention review and evaluation. The inclusion of different participants in each cycle was due to the inability of each participant to commit their time towards the research project due to other priorities despite the compensation provided in the form of work credits (for usability experts) and gift vouchers (for carers).

The first two cycles included usability experts who would pre-evaluate the intervention to ensure it is usable for the carer, while the remaining two cycles included carers. The evaluation was conducted using Likert Scales from 1 to 7, with open-end questions to understand user preferences in the design or practices to improve the overall intervention usability. The feedback received from each cycle was used to refine the intervention to ensure it is usable for the carer.

The evaluation survey was delivered in the form of a custom-built webpage that provides a step-by-step guide on the evaluation process for each cycle and the anonymous online survey. Each cycle took approximately 7-10 minutes to complete. The study obtained ethics approval from Deakin University HEAG before its start.

## 2.4 Study Instruments

The study survey was adapted from the User Experience Questionnaire (UEQ-S) [21] and the mHealth App Usability Questionnaire (MAUQ).[22] The UEQ-S was used by the usability expert to evaluate the user experience of the intervention. The UEQ-S includes 26-items on a 7 level Likert scale that are grouped into six categories. The UEQ-S instrument highlights user experience based on two dimensions, the pragmatic dimension that assesses perspicuity, efficiency and dependability of the intervention, and the hedonic dimension that focuses on the novelty and stimulation of the intervention. Additionally, the overall attractiveness of the intervention is calculated by combining the results from the pragmatic and hedonic dimensions as shown in **Figure 2**.[21] Furthermore, twenty-seven open-ended questions were included in the survey to gain user feedback regarding each aspect dimension to improve the experience for the carer.

The MAUQ was used by carers of individuals with a history of stroke to evaluate the usability of the intervention. The MAUQ was included as it is a valid and reliable instrument of 21 items on a 7 level Likert scale. The MAUQ highlights usability based on three categories: (i) ease of use and satisfaction, (ii) system information arrangement and (iii) usefulness.[22] In addition to the MAUQ survey, twenty-two open-ended questions were included based on each item to understand user preferences to improve system usability.

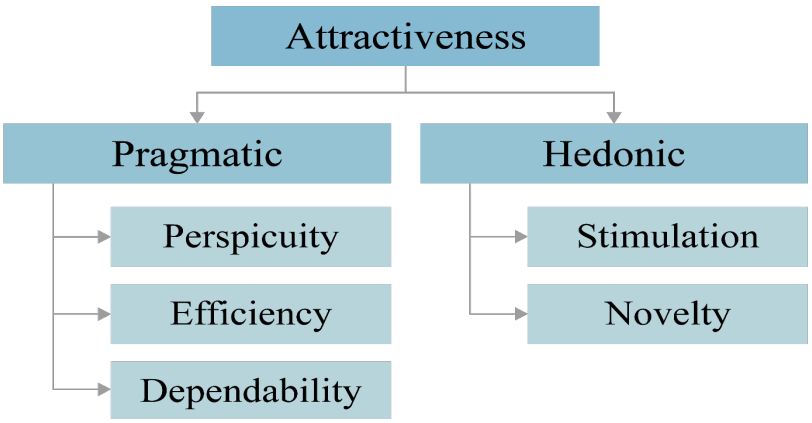



**Figure 2.** User Experience Questionnaire (UEQ-S) assumed scale structure [21]

## 2.5 Data Analysis

The survey responses from each heuristic evaluation were extracted in a Microsoft Excel sheet. The data collected from these responses were divided into qualitative and quantitative datasets. The qualitative data was analyzed using a grounded theory methodology that considers three phases: (i) open coding, (ii) axial coding, and (iii) selective coding.[19] Open coding is an analytical process that identifies different concepts, properties and dimensions in the discovered data. Axial coding is the process of relating the concepts into relevant categories and sub-categories. Selective coding is the process of refining and integrating the categories into theory to discover variations amongst concepts and enrich categories in terms of their properties and dimensions.[23] All phases considered were iteratively conducted by the primary author under the supervision of the other authors using NVivo 12 for data collected in each cycle. Furthermore, the quantitative data was divided into two parts, i.e., the demographic and heuristic data, which was analyzed descriptively using Microsoft Excel to highlight the mean overall impression based on individual domains.

**Table 1.** Demographic Characteristics of Survey Respondents (*N=20*)

| **Characteristic** | **Phase 1 (*N=5*)** | **Phase 2 (*N=5*)** | **Phase 3 (*N=5*)** | **Phase 4 (*N=5*)** |
|---|---|---|---|---|
| Participant Group | Expert | Expert | Carer | Carer |
| Age, years | | | | |
| 18-38 | 4 | 4 | 3 | 2 |
| 38-58 | 1 | 1 | 2 | 2 |
| 58+ | - | - | - | 1 |
| Sex | | | | |
| Male | 3 | 4 | 1 | 2 |
| Female | 2 | 1 | 4 | 3 |
| Education | | | | |
| Diploma | - | - | 3 | 1 |
| Bachelor's Degree | 3 | 4 | 1 | 1 |
| Master's Degree | 2 | 1 | 1 | 2 |
| Other | - | - | - | 1 |

# 3. Results

A total of 15 carers consented to participate in the study, of which 11 (73.33%) used the SeCr intervention, and 10 (66.67%) completed the follow-up questionnaire. The four carers who did not use the intervention found it difficult to participate due to their care commitments and the one carer who did not complete the follow-up questionnaire declined to continue participation as their loved one's fell too ill. Carers ranged in age from 24 to 61 years (mean = 41.7; SD = 14.2), the majority were female (70%) and held a tertiary-level qualification (80%). On the other hand, all usability experts (n=10) who consented to participate in the study used the SeCr intervention and completed the follow-up questionnaire. The usability experts ranged in age from 30 to 49 years (mean = 34.6; SD = 5.8), the majority were male (70%), held a masters (30%) or bachelors (70%) degree and had usability experience of more than 2 years (90%). **Table 1** outlines the fully demographic characteristics of the sample included in this study.

## 3.1 Heuristic Evaluation and User Preferences

Four iterative cycles of heuristic evaluations and intervention reiterations were conducted during a 7-week (August - September 2021) iterative design cycle, including ten usability experts and ten carers of individuals with a history of stroke, respectively. Users in each cycle were briefly introduced to the intervention, and were then instructed to use the intervention for a single day according to their needs. At the end of the day, users would provide feedback using an online survey that would be used by the primary author to re-iterate the intervention. On average each cycle of feedback and design re-iteration took about 1.5 weeks.

*Iterative Cycle 1.* Five usability experts with an average usability experience of 5.2 years participated in the heuristic evaluation based on the UEQ-S survey instrument. Three male and two female usability experts participated in this cycle, with ages ranging from 32-39 years (mean = 34.8; SD = 2.68), as shown in **Table 1**. The usability experts in this cycle demonstrated concerns regarding *the text size* and *users understanding of the icons* used with the intervention. Furthermore, some usability experts described the need to make *the social aspect more encouraging and motivating* and provide features that a*llow the carer to track their health progress*. Despite these concerns, the outcomes of the UEQ-S scale demonstrated that the usability experts rated the intervention highly in terms of attractiveness, perspicuity, efficiency, dependability and stimulation. However, a majority of the usability experts have a negative opinion in terms of novelty, as shown in **Figure 3**.

Using these findings, the intervention prototype was improved in its next iteration. The key modifications included: (i) increase in font size, (ii) use of standardized icons, (iii) separate page for health tracking, and (iv) inclusion of likes and comments section within the social media page to encourage and motivate the user.

*Iterative Cycle 2.* Five usability experts with an average usability experience of 2.6 years participated in the heuristic evaluation based on the UEQ-S survey instrument. Most participants were male (N=4; 80%), with ages ranging from 30-49 years (mean = 34.4; SD = 8.26), as shown in **Table 1**. In this cycle, a majority of the usability experts was satisfied with the intervention. However, one expert discussed *the need to make the intervention unique from other technologie*s. This promoted the integration into the intervention of a feature of "MicroApps" to provide the carer with the *freedom to choose and install the service that best suits their needs* for health monitoring for themselves and their loved ones. The satisfaction of the usability expert was evident in the outcomes of the UEQ-S scales, which demonstrated positive results for attractiveness, perpetuity, efficiency, dependability and stimulation. However, the usability experts continued to have a neutral opinion concerning the novelty with a slight change in the outcomes, as shown in **Figure 4**.

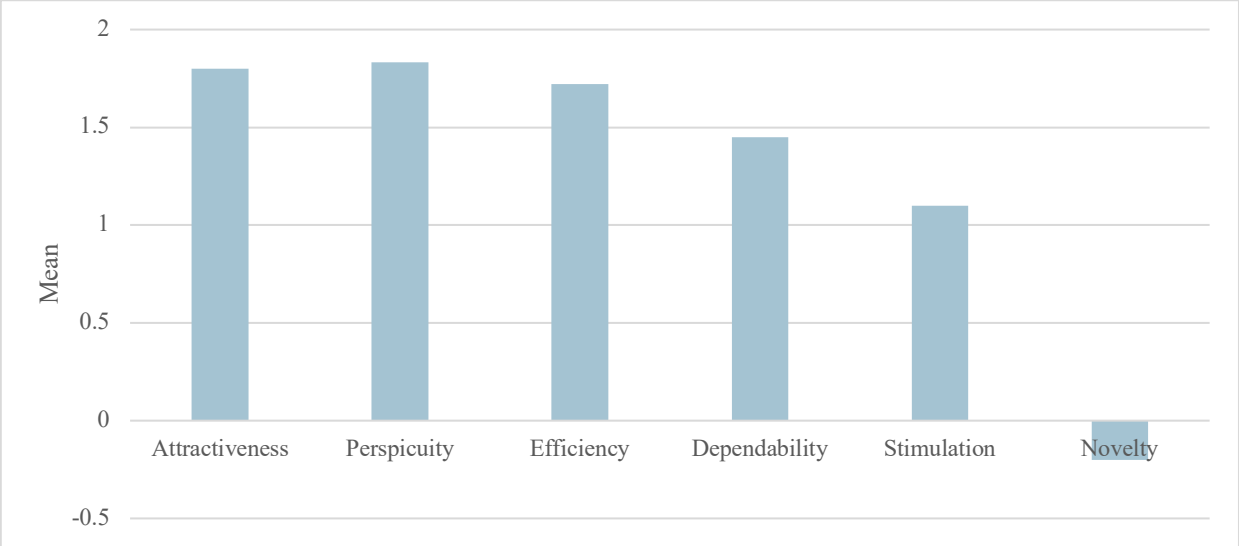



**Figure 3.** UEQ-S outcomes for Cycle 1 with mean ranging from 1 to 3

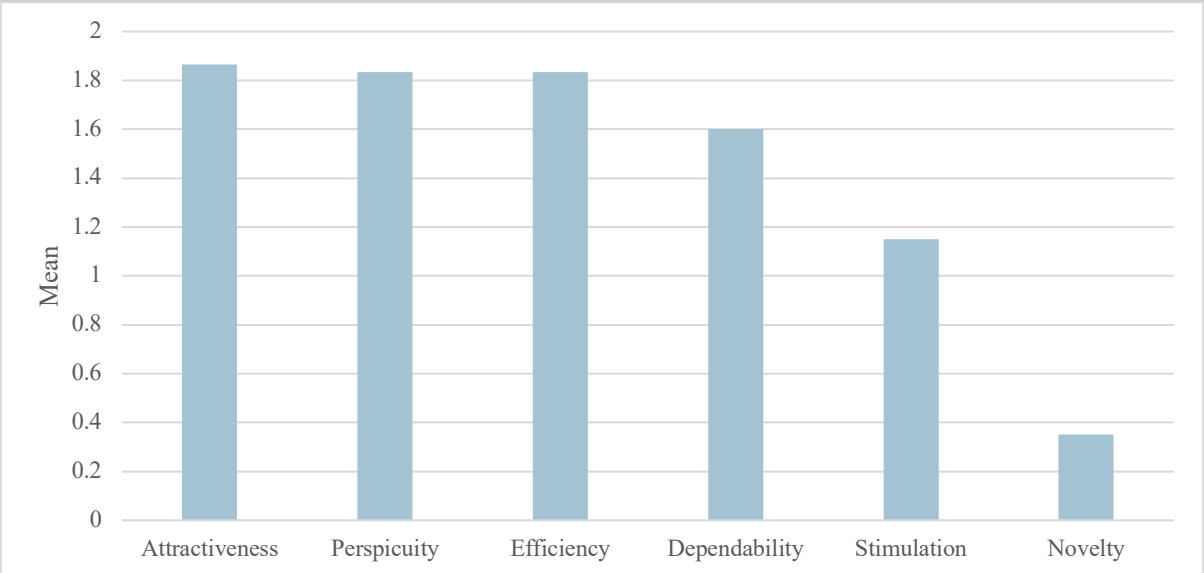



**Figure 4.** UEQ-S outcomes for Cycle 2 with mean ranging from 1 to 3

*Iterative Cycle 3.* Five carers participated in the heuristic evaluation based on the MAUQ survey instrument. Four female and one male carer(s) participated in this cycle, with ages ranging from 24-56 years (mean = 38.2; SD = 13.6), as shown in **Table 1**. In this cycle, carers discussed several concerns about the usability of the intervention. Issues were predominately on the information page. Some carers debated the issues with the *font size, image quality*, and *loading times*. Others discussed the need to have *categories for each topic* to allow easy searching. Other suggestions provided by the carers include having *an emergency call option* for nearby hospitals, knowing if the user *positing or answering content is genuine* to prevent misinformation, and the inclusion of *personal healthcare professionals* to communicate their needs.

**Table 2.** Critical usability issues based on the usability items in the MAUQ scale

| Items | Mean |
|---|---|
| Whenever I made a mistake using the app, I could recover easily and quickly | 4.8 |
| This app has all the functions and capabilities I expect it to have | 4.8 |
| The information in the app was well organized, so I could easily find the information I needed. | 5 |
| I feel comfortable using this app in social settings | 5 |
| The amount of time involved in using this app has fitted for me | 5.2 |
| I would use this app again | 5.2 |
| Overall, I am satisfied with this app | 5.2 |
| I like the interface of the app. | 5.2 |
| This mHealth app provided an acceptable way to receive health care services | 5.2 |
| The app adequately acknowledged and provided information to let me know the progress of my action | 5.2 |
| Using the app, I had many more opportunities to interact with my health care provider | 5.2 |
| I felt confident that any information I sent to my provider using the app would be received | 5.2 |
| I felt comfortable communicating with my health care provider using the app | 5.2 |

To address these concerns, the information pages were updated to present the information more clearly, and loading times were optimized. Information related to the nearby stroke clinics were added, with the option to call the clinic should there be an emergency. As the intervention was a prototype and did not consider user account creation, it was challenging to provide a feature to determine the authenticity of the user, and hence was not considered in this cycle of intervention refinement. In addition to this, personal healthcare professionals could not be considered in this cycle as the intervention is in its early stages of development. However, the introduction of the mHealth intervention step of iterative cycle 4 was updated to ensure the participant is aware of the following stages of the research and the possibility for the inclusion of healthcare professionals. Similar concerns demonstrated in the user feedback was evident in the MAUQ survey items, as shown in **Table 2** based on the mean score, while **Figure 5** presents the impact of these concerns on the overall usability.

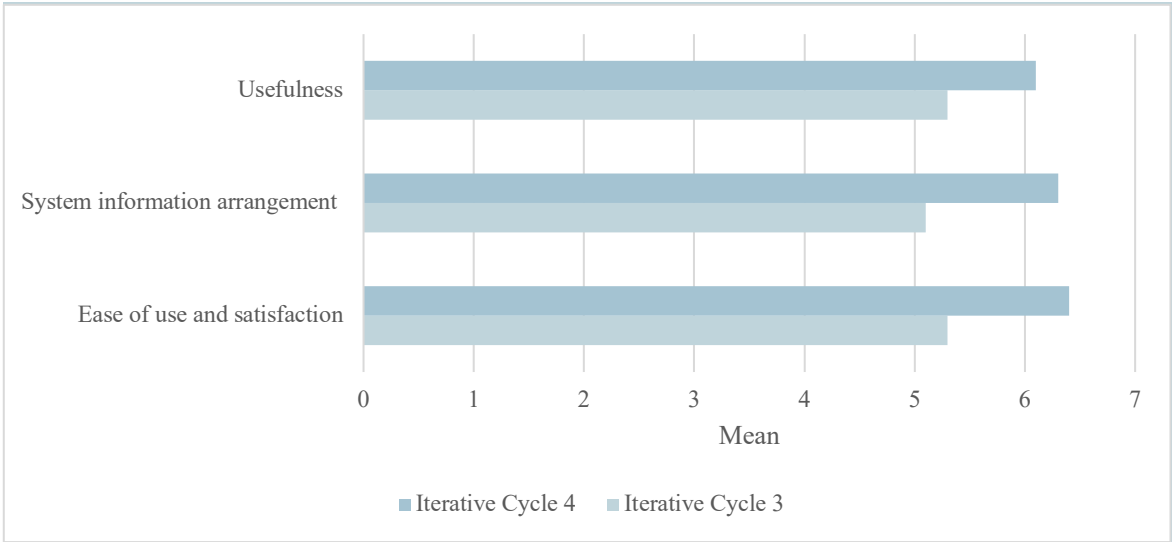



**Figure 5.** Heuristic evaluation based on carer survey with mean ranging from 1 to 7

*Iterative Cycle 4.* Five carers participated in the heuristic evaluation based on the MAUQ survey instrument. Three female and two male carers participated in this cycle, with ages ranging from 28-61 years (mean = 45.2; SD = 14.9), as shown in **Table 1**. In this cycle, carers discussed the *need for more personalized information*, including nutrition and psychological factors, to monitor to pre-diagnose an impending stroke. Moreover, some carers discussed the need to *import blood reports and medication*. In contrast, one carer discussed the possibility of having support functions within the intervention *to receive professional help in case of an emergency*. Despite several carers discussing various needs, the carers were satisfied with the intervention, as demonstrated in **Figure 5**. The only known usability issue within the intervention was identified by the item 'the app adequately acknowledged and provided information to let me know the progress of my action' (mean = 5.4; SD = 0.9).

# 4. Discussion

This study performed a heuristic evaluation on an earlier designed prototype for carers of individuals with a history of stroke and to identify their preferences in technological design. Our findings indicate that iteratively revising the intervention based on expert and user feedback significantly improved the usability and user experience of the prototype. Further, it is important to note the necessity for including usability and user experience heuristics in stroke caregiving, as mHealth apps that support stroke caregiving in the past have described the inability of designers to consider user needs and preference in the design, which leads to reduced acceptance and adherence.[15]

Another finding is the similarities in usability experts and carers opinions in terms of presentation, font size and image quality. While experts primarily focused on uncovering issues related the design and presentation, the critical focus (or discussion) of carers were based on the features that support information and communication. The differences in opinions were expected due to the lack of understanding of the expert with regards to stroke caregiving. However, this finding describes the importance of including the carer (s) in the design and development process to ensure improved acceptance, which is rarely considered as described in the user reviews of previously published mHealth interventions that support carers of individuals living with stroke.[15]

In terms of the carers' information and communication needs; several studies in the past have assessed its potential,[10, 11, 24, 25] with carers describing being satisfied with the intervention as it supported their demands.[10, 11, 24] However, despite the past studies exploring needs to support the information and communication needs of carers, the carers in this study described the need for personalized information support and for communication with their healthcare team, i.e. the individuals who are aware of their situation. These aspects were not described in past studies, which could be critical in the carers acceptance of the technology.

A further critical aspect that may affect the carers acceptance of the mHealth technology is trust. In the different stages of the heuristic evaluation, trust was a key point of discussion amongst the carers. The discussion of trust was based on the information available, user answering and communicating information, intervention does not fail at the time of need and safety of their data. Trust is considered an essential determinant for technology adoption and influences its acceptance.[26, 27] Studies suggest that users often hesitate to share their personal information with unfamiliar suppliers due to the fear of misuse of data.[28] As a consequence, it affects the way users interact with the technology.

## 4.1 Future Work

Evans et al. [29] argues for the potential of building relationships through co-design practices may facilitate trust between the various stakeholders and help understand the problems faced by the target group. Moreover, it will help develop mechanisms to support their needs and

aspirations over time. The potential of co-design in facilitating user trust was evident in this study, with carers discussing practices that the researchers can use to ensure they feel safe to use the intervention.

Co-design practices can facilitate user trust and form a partnership between the researcher and the stakeholder to work together in all aspects of intervention development, which includes needs assessment, development, pilot testing, and dissemination. [30] The co-design process is relatively new within stroke caregiving literature, and the concept has the potential to improve technical design and develop service improvements for carers.[31] Hence, the process needs to be considered by future researchers to create interventions that are meaningful, actionable, and feasible interventions for the carer.

### 4.2 Limitations

The study has some limitations. First, the researchers recruited usability experts from Amazon mTurk based on defined criteria. However, it is challenging to validate the authenticity of the usability experts credentials within this platform, and hence the outcomes highlighted by usability experts need to be considered with caution. Second, the inability of the researcher to physically conduct a workshop to monitor stakeholder interactions and get real-time feedback. This was due to the local restrictions required for social distancing to limit the spread of the disease. Third, the small sample size made it difficult to draw statistical conclusions, which may have uncovered several usability issues and bugs that may otherwise not be evident. Finally, the limited time provided to the carer to use the intervention. Due to the short duration of the project, the carer was provided only one day to interact with the intervention that was not sufficient to conduct a comprehensive heuristic evaluation. However, as this is a pilot evaluation, we aim to perform a more comprehensive future evaluation with real life interactions and integration of the intervention in the daily activities of the carer to determine its acceptance and effectiveness in supporting carers of individuals with a history of stroke.

## 5. Conclusions

mHealth interventions can support carers of individuals with a history of stroke if it addresses their needs and expectations. Some of the critical needs and expectations identified in this study include a comprehensive, personalized information platform, communication with their healthcare teams, and a private system or that the carer can trust. The findings suggest that there is still room for improvement, creating a more inclusive environment for carers through co-design practices to evaluate the intervention based on their needs and identify issues to ensure that the final product developed is usable and meaningful for the carer.

## Abbreviations

App: Application; mHealth: Mobile Health; GATT: Generic Attribute Profile;

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## Contributorship

All authors designed and conceptualized the study, and were involved in developing the protocol, gaining ethical approval and participant recruitment. EL developed the mHealth app

and coordinated with the participants at different iterative cycles to update and ensure it addresses their needs and requirements during the care trajectory. EL performed these activities under the supervision of MA, JG, FK and AF. Further, EL wrote the first draft of the manuscript. All authors reviewed, edited and approved the final version of the manuscript.

## Conflicts of Interest

The authors declare that they have no competing interests.

## Ethical approval

Not applicable to this study.


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## Guarantor

Not applicable to this study.

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