mHealth: Where Is the Potential for Aiding Informal Caregivers?

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Abstract. The health and well-being of informal caregivers often take a backseat to those that they care for. While systems, technologies, and services that provide care and support for those with chronic illnesses are established and continuously improved, those that support informal caregivers are less explored. An international survey about motivations to use mHealth technologies was posted to online platforms related to chronic illnesses. We focused on responses regarding the facilitators and challenges of achieving health goals, including the use of mHealth technologies, for the subgroup who identified as "Caregivers". Findings indicate that mHealth technology is not yet the most important motivational factor for achieving health goals in this group, but greater future potential is suggested.

Keywords. Caretakers, chronic, diabetes, sickle cell, motivation, self-management

1. Introduction

Informal caregivers play a crucial role in the complex network surrounding the care of those with chronic illnesses. These caregivers are defined as family members, friends, or other community members who provide practical, physical, and psychological support for those with chronic illnesses. Formal healthcare providers receive years of training, medical and administrative staff, technologies tailored to their needs, protocols, and financial support - support that informal carers are often not provided [5]. As the demand on healthcare systems continues to surpass the supply of medical resources, this excess demand spills over into the responsibility of informal carers [3].

The 2016 European Quality Of Life Survey (EQLS) revealed that the prevalence of informal carers varies greatly by country (10%-33%) [11]. The EQLS also highlighted that 27% of working caregivers and 41% of unemployed caregivers reported being "In fair or bad health" [11]. Caregiver burden is characterized by both physical and psychological symptoms and disorders associated with, or resulting from, the stress of providing 20+ hours of care per week - varying greatly between diagnosis groups of those whom they care for [1]. According to the Center for disease control (CDC), Informal caregivers themselves are at risk for developing chronic illnesses such as

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depressive disorders, diabetes, cancer, coronary heart disease, with approximately 41% of caregivers reporting being diagnosed with 2+ chronic illnesses [2]. While little formal support or interventions are designed to aid or understand the needs of caregivers, mobile and digital health interventions have the potential to support one's own health self-management as well as their tasks as caregivers [9]. Caregiver motivation is, and only recently, directed at those whom they care for [4]. We aim to contribute to this foundational knowledge by introducing concepts that have yet to be explored at length to contribute to the design of further research.

In this paper, we present selected results of and international cross-sectional online survey, "Motivation in mobile health", regarding personal health, motivational factors, and use of mHealth technologies for self-management with the focus on self-reported caregivers. The purpose of focusing on this subgroup is to highlight the unique needs of those who are caretakers and those who are caretakers with chronic illnesses, and to put these fourth as potential focus areas for mHealth development.

2. Methods

The online survey was distributed on social media forums related to sickle cell disease (SCD) or diabetes (n=9 online platforms total). We used results from 16 in-person interviews to derive questions for the survey [10]. Announcements in either English, Norwegian, or French language called for respondents to answer questions about what motivates them to self-manage their own health or illness. Questions (n=38) were separated into seven categories with the following headings: 1) background and health goal questions, 2) use of wearables and sensors, 3) use of mobile apps, 4) data-logging, 5) data sharing and data integration, 6) social media and entertainment factors, and 7) demographic questions including age, gender, chronic disease diagnosis. Questions about "with who do you prefer to discuss health issue", and caretaker status were added to this last section of the survey after the first 257 respondents answered. The online survey was open for data collection between November 2018 and March 2020. Primary results comparing those with and without chronic illnesses have been previously published [10] and further details about the questionnaire are available at DataverseNO [6].

While caregivers were not the primary target group for this survey, questions regarding whether a person was a caregiver, whom they provided care for, and whether they had a chronic illness themselves were placed at the end of the survey. In doing so, we were able to gather the same and comparable information on all respondents, which also limited the bias of such relationships on their previous responses regarding the perception of their own health, access to quality health information, use of mHealth technologies. A request for ethical approval was reviewed by Veronica Sørensen at the Regional Ethics Committee (REK) and found to be exempt from their purview (ref. 2017/562).

3. Results

A total of 539 people responded to the online survey that included questions about being a caregiver, 72 of whom reported being caregivers (n=46 had a chronic disease

themselves, n=24 who had no chronic disease, and n=2 who left this question blank). These respondents (n=46 female, mean age 39.8 years; n=20 male, mean age 42.8 years, n=6 did not disclose their gender, mean age 28.6 years) represented n=25 countries (n=30 USA, n=11 Norway, n=8 UK, n=2 Australia and n=1 for remaining countries). Caregivers reported caring for those with SCD (n=9), diabetes (type I: n=9; type II: n=4), and other chronic illnesses (n=40). Results are divided into two groups, i.e. *Caregiver only* or a *Caregiver with chronic illness*. Table 1 describes caregivers' primary health goals, given the following options: to Avoid illness, Improve illness, Recover from existing illness, or Other health goal.

Table 1. Caregivers' primary health goals

Primary health goal	Caregiver only (n=24)	Caregiver with chronic illness (n=46)	Caregivers (n=72)*
Avoid	65%	41%	50%
Improve	23%	37%	32%
Recover	8%	17%	14%
Other	4%	4%	4%

*Includes two caregivers who left the question "do you have a chronic illness" blank.

As can be seen in Figure 1 the two groups rated the importance of the eight motivational factors very similarly (no group difference, F<1, p=.61, no interaction, F<1, p=.81). Apart from the access to Advanced/relevant technology all other goals are rated as very important (this difference between factors was significant, $F(4.373, 240.516)=8.33$, $p<.001$).
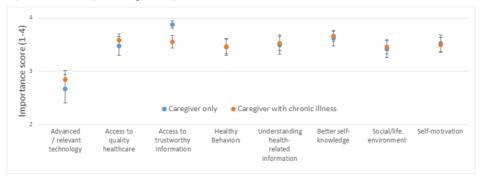

Figure 1. Importance of factors to achieve one's primary health goal (multiple-choice). Error bars denote SEM

As shown in Figure 2, the groups *Caregiver only* and *Caregiver with chronic illness* demonstrated similar distributions in the category "Challenges of achieving one's primary health goal" related to their experienced Limited options for technology, Lack of time, and Lack of health knowledge, yet differed in reported challenges of Motivation (38% and 28% respectively), Lack of social support (0% and 9% respectively), Lack of access to quality healthcare (17% and 28% respectively), and Other (13% and 5% respectively).
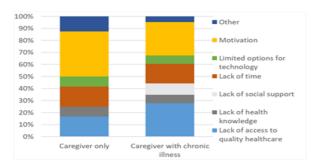
Figure 2. The greatest challenge to achieving one's primary health goal, by group

Of all caregivers, 65% reported using one mHealth technology, 15% used two, 14% used three, and 5% used four or more mHealth technologies. Table 2 shows the distribution of which technologies caregivers use. Most of those in the *Caregiver only* group used Sensors (integrated into the smartphone, e.g. geolocation, stress tracker) and Other devices, whereas those in the *Caregiver with chronic illness* group used mostly Medical devices and Apps.

Table 2. Percentage of caregivers who use mobile health technologies, by group

Technology used	Caregiver only (n=24)	Caregiver with chronic illness (n=46)	Caregivers (n=72)*
Sensors	38%	26%	29%
Activity trackers	33%	33%	32%
Apps	29%	39%	35%
Medical devices	13%	46%	35%
Other devices	42%	22%	29%

*Includes two caregivers who yet left the question "do you have a chronic illness" blank.

Table 3 illustrates the different reasons respondents had for collecting data using their mHealth technologies. The biggest differences were related to the reasons of Competition and Other, which were favored by those in the *Caregiver only* group, and Tracking progress, which was favored by the *Caregiver with chronic illness* group.

Table 3. Caregivers' reasons for using mHealth technology to gather data, by group

Motivations	Caregiver only (n=24)	Caregiver with chronic illness (n=46)	Caregivers (n=72)*
To track progress	67%	78%	74%
To share data	25%	26%	25%
Competition	17%	4%	8%
To learn	71%	76%	74%
To receive feedback	29%	35%	32%
Other	17%	2%	7%

*Includes two caregivers who yet left the question "do you have a chronic illness" blank.

The two groups, *Caregiver only* and *Caregiver with chronic illness,* also reported preferring to seek health information from the following sources: healthcare providers (50% and 46% respectively), Carers (0% and 4% respectively), or online (33% and 39% respectively).

4. Discussion

Caregivers represent an unmet group of potential users of mobile and digital health technologies with unique and diverse needs. However, our data (Figure 1) shows that technology is not yet a particularly motivating or facilitating factor when it comes to achieving their health goals. The fact that 65% of caregivers reported using one mHealth technology, and that both groups reported collecting data to track their progress and learn about their health, suggests there is potential for these technologies to become a greater factor in achieving health goals, e.g. by supporting other factors which they already deem important. While overall caregivers primarily wish to avoid illness, those who are only caregivers favor avoiding, whereas those who were caregivers with a chronic illness favor improving or recovering from existing illness. Other differences seen throughout the results could be potentially significant in larger sample sizes and should be explored in future research.

Limitations: the following factors contributed to a relatively small sample size of caregivers: i) the language of the recruitment analysis, i.e. describing health in terms of "illness" or "disease", may have deterred those who otherwise would have responded to the more general term "health", ii) the survey did not specifically target caregivers, iii) the recruitment platforms were primarily related to diabetes and sickle cell disease, and iv) the survey was only available in English, Norwegian, and French.

Considerations for future research: Because caregivers can perceive their duties as positive and fulfilling, stressful and burdensome, or anywhere in between, a person's attitudes can highly influence their capacity and willingness to take care of themselves. While static information about how to care for oneself while caring for others is available, technology has the potential to make this more accessible [7]. While unexplored in this survey, it has been noted by others that a person's country of residence, their associated medical systems, and cultural factors also affect their perception of their role as a caregiver, as well as their personal capacity and practical ability to additionally care for themselves [8]. By targeting the unique needs of caregivers, when caring for themselves and others, mHealth technologies also have the potential to help that person -manage their own health. Therefore, future research about the needs, priorities, and challenges of caregivers and the design and development of mHealth technologies should consider these factors.

5. Conclusion

As anyone who is ever flown in a plane knows, safety presentations instruct us to help ourselves by putting on our own oxygen mask first before assisting others. After all, we are no good to anybody if we are incapacitated. Therefore, it is just as important to understand the needs and risks of caregivers, a crucial group of stakeholders related to not only their ability to care for their friends and family with chronic illnesses but also themselves.

This survey has gathered a diverse set of information. We encourage our fellow researchers to contact us to discuss and collaborate on future analysis.

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