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Potential assistive technology preferences of informal caregivers of people with disability

Oladele Atoyebi[1,2], **Maude Beaudoin**[3,4], **François Routhier**[3,4], **Claudine Auger**[5,6], **Louise Demers**[5,7], **Andrew Wister**[8,9], **Michelle Plante**[7] and **W Ben Mortenson**[1,2]

Abstract

Background: Preferences of informal caregivers of people with neurocognitive disorders for technological solutions are important in user- centered design approaches. It is crucial to take into consideration the needs and preferences of users when developing new technology to facilitate their uptake.

Objectives: The objective of this study was to determine caregiver preferences for potential technological solutions to help address their needs and compare technology preferences of caregivers who provide care to those with and without neurocognitive disorders (NCD).

Methods: This was a quantitative descriptive study. We surveyed informal caregivers of older adults with disability in Canada. Participants were asked to answer questions about their preferences for 10 potential technological solutions that could be developed to make caregiving easier.

Results: Data from 125 respondents (72 caregivers of people with NCD and 53 caregivers of people with non-NCD-related disabilities) were analyzed. Generally, caregivers preferred web-based solutions as these were among the first five choices for both groups combined. However, there were some differences in the order of preference of potential solutions in both groups.

Conclusion: Informal caregivers of people with NCD preferred web-based solutions to help address their needs.

Keywords

Preferences, user-centered design, neurocognitive disorders, informal caregiver

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[1]University of British Columbia, Vancouver, Canada
[2]GF Strong Rehabilitation Research Program, Vancouver, Canada
[3]Centre for Interdisciplinary Research in Rehabilitation and Social Integration, Centre Intégré Universitaire de Santé et de Services Sociaux de La Capitale-Nationale, Québec City, Canada
[4]Université Laval, Québec City, Canada
[5]Université de Montréal, Montréal, Canada
[6]Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, Montréal, Canada
[7]Centre de Recherche de L'Institut Universitaire de Gériatrie de Montréal, Montréal, Canada
[8]Gerontology Research Centre, Vancouver, Canada
[9]Simon Fraser University, Vancouver, Canada

Corresponding author:
Oladele Atoyebi, University of British Columbia, Vancouver V6T 1Z4, BC, Canada.
Email: oladeleatoyebi@alumni.ubc.ca

Introduction

Older adults living with a cognitive or physical disability often receive care from a relative or friend who in such instances takes up the role of informal caregiving. Informal care occurs in different forms, including physical assistance with activities of daily living, planning to access services, and emotional support.[1] Caregiving may provide caregivers with a sense of accomplishment and in some instances improve the quality of the relationship between the caregiver and care recipient.[2,3] However, informal carers frequently need to contend with mental and physical stress. For example, compared to non-caregivers, informal caregivers are more likely to experience depression, poor personal health, burnout, and disruptions to careers.[4,5] The level of stress caregivers experience is associated with the type of disability and degree of dependence of the care recipient.[6]

Providing care for an older person with a cognitive disability such as neurocognitive disorder (NCD) can be challenging. For example, people with dementia may need ongoing continuous surveillance. In addition, caring for a person with dementia at home may represent a high-risk situation for informal caregivers that makes them susceptible to adverse health consequences such as depression and physical stress.[7] Hence, it is important to find effective supportive strategies, especially when caring for people with NCD such as dementia.[8]

While many programs, policies, and technological products are being created to support the care of people with disabilities, caregiver input in the creation of these products is often limited.[9] It is important to identify the specific needs of caregivers and match these to the appropriate interventions or solutions. For instance, caregivers of people with NCD report needing better information and other resources that could aid their caregiving tasks such as assisting with activities of daily living.[10,11] Identification of caregiving needs should guide the development of solutions to address them.

Assistive technology (AT) is one means to make caregiving easier. Informal caregivers who use AT report peace of mind knowing when the needs of the person they support have been addressed.[12] The use of AT designed for persons living with a disability can help promote independence and reduce the burden of care, thus potentially reducing the number of hours of help needed from an informal caregiver. The need for lesser hours of assistance reduces dependence on the caregiver and lowers caregiver stress. In addition, key AT can help make care planning more seamless.[13–15] For instance, electronic equipment such as smartphones and computers can be used to coordinate care.[16] Similarly, an experimental study of the impacts of AT on users and their informal caregivers found users found it significantly decreased care burden.[17] Thus, several forms of technology including telephones and web-based resources have the potential to improve the well-being of caregivers by reducing the burden associated with caregiving.

Using user-centered design to develop technological solutions is an optimal way to ensure the interventions are acceptable to end-users.[18] However, this approach has not been used extensively with informal caregivers. Given that user involvement is central to the design of technology that is both relevant and useful, prioritization of solutions by caregivers of people with disability is a vital step towards designing the solutions they need.[18]

This multi-site (British Columbia and Quebec) cross-sectional study built on information from preliminary research that identified the specific needs of informal caregivers of older people with disability in terms of aspects of caregiving that they find most burdensome such as helping with bathing, mobility, and constant monitoring.[12] In the previous study, 56 potential technological solutions to address the needs of informal caregivers were identified by potential users (caregivers and care recipients), out of which 10 were shortlisted[19] through a consensus-building process[20] involving researchers, engineers, and clinicians. This list of potential technologies includes solutions that can be used directly by caregivers to manage tasks and those that are useful for maintaining the independence of care recipients to relieve the caregiver. Some of the potential solutions are web-based platforms versus hardware, while some are devices meant for use by care recipients and indirectly by caregivers. The full list of technologies included in the survey is on Table 1.

The study was intended to illuminate the implications of the context of care on the solution preference of caregivers. The objective of this research is to determine caregivers' prioritized preferences for potential technological applications to support caregiving activities for care recipients with NCD. The potential solutions were conceptualized in collaboration with caregivers and care recipients in a previous study.[19] In addition, we compared the potential technology preferences of caregivers who aid those with and without NCD.

Methods

This was a quantitative descriptive study. We used a web-based survey to identify and rank the technology preference of caregivers in two groups: those taking care of people with NCD and a second group taking care of people without NCD. Institutional Review Board approvals were obtained from the local university (#H15-01,164) and health authority research ethics boards. Our presentation of survey findings was guided by an adaptation of the Checklist for Reporting Results of Internet E-Surveys (CHERRIES).[21]

Table 1. List of potential technological solutions.

1. Website for recruiting healthcare provider/ aid	The website would have information about healthcare providers It would include downloadable questionnaires that informal caregivers could use to assess the skills of healthcare providers
2. Website for social activity	This website would list local social events and leisure activities (e.g., where other caregivers and care recipients may meet each other)
3. Website for assistive technology training for caregivers and users	The website would offer training on how to assemble, install and use different assistive technology (e.g., use of bathtub seat, wheelchair, or scooter)
4. Website for counselling	This website would provide informal caregivers and care recipients with online counselling options. You would be able to book appointments with a certified person for counselling at your convenience
5. Smart stairway railing	The handrail would light up as one climbs or descends the stairs. The steps would also be illuminated with light
6. Meal container	This container (thermos or lunch box) would keep meals hot or cold. It would be easy to handle and open
7. Posture monitoring device for wheelchair users	This posture monitoring device on a wheelchair would use verbal, visual or vibration cues to guide users to adjust posture
8. Smart braking system for walkers/walking aid devices	To improve safe operation, this braking system on walkers would be activated or deactivated depending on the intention of the user (e.g. brakes will be deactivated when they initiate movement and activated when they sit)
9. Smart cane/walker with a wearable bracelet	The smart cane/walker would have a bracelet. The bracelet would vibrate (buzz) if the user goes more than five feet (or 1.5 m) from the cane/walker (so that they remember to use their device and not leave it behind)
10. A personalized cab service for transportation	This service would provide a consistent driver (with an adapted vehicle) who is familiar with the needs of the person you assist

Survey design

The survey was developed following the method described by Glasgow (2005) and refined after two cognitive interviews and a pilot testing with caregivers to ensure reliability. To obtain representation from speakers of both Canadian official languages, the survey was translated from English to French by the Quebec team and made available in both languages before circulating the survey link to caregiver groups. The survey was subjected to an expert panel review to improve content validity. The questionnaire was pre-tested among 5 informal caregivers to ensure its clarity and suitability to the target population. Necessary amendments were made before the questionnaire was used for the actual study.

Participants

In the current study, informal caregivers of those living with disability were involved to prioritize the most preferred technologies. A convenience sample of Canadian adults in British Columbia and Quebec, aged 19 and above (18 and above in Quebec) was recruited who were either current or past caregivers of an older person with disability. Participants needed to be able to communicate in French or English and the completion of the survey served as their consent to take part in this study. NCD was defined based on the fifth edition of the American Psychiatric Association's diagnostic and statistical manual of mental disorders.[22] Respondents were asked whether the care recipient's diagnosis of NCD had been made by a health professional according to a similar question in the Canadian Community Household Survey.[23]

Recruitment

Respondents were recruited by the authors via caregiver support groups across the country as well as through social media, disability and diagnosis specific organizations newsletters, and word of mouth. Study poster was displayed around [*anonymized*] and study brochures were handed out to interested individuals. Interested caregivers were directed to the online survey via a link in the study advertisement. A study information page preceded the online survey described the study (e.g. aims and time requirements) and explained that completion of the survey served as consent.

Data collection

An online questionnaire was used to collect quantitative data from informal caregivers. In the survey, caregivers answered questions about the importance of the 10 shortlisted solutions to meet their specific needs. The survey requested participants to identify the reason for any preferences stated and to provide their perspectives on the relevance of each solution.

Table 2. Survey administration.

Number of Items	The survey had three preliminary pages and two sections (A and B). The preliminary section included the information page and a page where participants chose whether they wanted to complete the survey as a caregiver or care recipient Section A consisted of the survey on potential solutions while section B asked about the sociodemographic characteristics of participants
Adaptive questioning	Use adaptive questioning was used for certain items and some questions were only conditionally displayed based on responses to previous items related to them. This format helped to reduce number and complexity of the questions
Time/Date	Survey piloting was carried out from January to February 2019 to fine-tune the questionnaire. After final corrections were made to the survey based on information received during the piloting, data was collected over a period of 8 months between June 2019 and February 2020
Incentive	Participants were offered an optional incentive, which is the possibility of winning one of three gift cards if they provide their email after the survey
Completeness check	Survey items had a non-response option such as "not applicable" or "rather not say" where applicable and selection of one response option was enforced. Participants had to answer a question before they could go on to the next page
Review step	Participants were able to review and change their answers by clicking on a back button

Sociodemographic data and information about caregiving activities of participants were also collected. The survey provided the perspective of caregivers on the rating of technological solutions that are meant to make caregiving easier. Respondents were deemed to have participated in the survey if they answered a minimum of one preference rating question pertaining to at least one of the potential solutions. Thus, participants were included in the analysis if they indicated how important they would find at least one of the 10 solutions in the survey. Other considerations pertaining to survey administration are displayed on Table 2.

Data analysis

Descriptive statistics for quantitative measures such as age and mean hours spent working or providing care were calculated. Preference ratings were allocated to the technological solutions according to their importance based on caregiver responses. The survey was presented as a Multiple Rating Matrix and the comparison of alternative solutions was conducted using the Pugh matrix analysis.[24,25] The formula: Σ Rank (r)* multiplier = rank score was used to estimate a rank score (rs) for each of the solutions. The multiplier were numbers 1–5 corresponding to the rating options (not at all, slightly, moderately, very much, and extremely) under the question that asks how important participants think it would be to develop a solution.

The solutions were ranked to determine the most preferred technology. Characteristics of caregivers of people with NCD were compared with those caring for people without NCD using the Kruskal Wallis and t-tests.[26,27] Data collected from this survey were analyzed with Microsoft Excel and SPSS version 24.

Results

A total of 142 participants completed the online questionnaire. Of these, data on rating of at least one of the solutions were available for 125 participants as 17 respondents started the survey but did not rate any of the solutions and were excluded from our analyses. Of the 125 completed surveys, 67 were completed in English and 58 in French. Table 3 shows the demographics for participants that participated in the rating process. The differences found within groups were assessed with Kruskal Wallis and t-tests and are displayed on Table 3.

Most of the participants were female although the NCD group had a higher proportion of female participants and were significantly younger than the non-NCD group.

Caregiver respondents were mostly spouses/common law partners, Caucasian and lived with their care recipients in both groups. Caregivers in the NCD group were less likely to have assisted the care recipient for a longer period although they provided care for more hours per week to care recipients that were significantly older than their counterparts in the non-NCD group.

Overall preferences of all participants

Figure 1 displays the ranking of solutions preferred by all participants involved in this study, including caregivers providing care to people with and without NCD. In general, the web-based resource for hiring paid healthcare aids was the most prioritized (rank score = 494)

Table 3. Demographics of participants.

	Care recipient has NCD N (%) M±SD *n* = 72	Care recipient non-NCD N (%) M±SD *n* = 53	p[a]
Female	59 (81.9)	41 (77.3)	0.001
Mean Age	62.9±13.6	66.1±14.2	0.041[b]
Married/Common law	52 (72.2)	35 (66.0)	0.005
Ethnicity			
Caucasian	55 (76.4)	37 (69.8%)	0.216
Language			
English	39 (54.2)	28 (52.8)	0.001
Highest level of education	—	—	0.020
University degree at and above bachelor's level	29 (40.3)	16 (30.2)	—
University degree below bachelor's level	8 (11.1)	7 (13.2)	—
College or other non- university certificate	16 (22.2)	6 (11.3)	—
High school diploma or equivalent	5 (6.9)	9 (17.0)	—
Less than high school diploma/equivalent	2 (2.8)	2 (3.8)	—
Employed	30 (41.7)	17 (32.1)	0.001
Annual household income	—	—	0.006
<$14,999	5 (6.9)	5 (9.4)	—
$15 000 - $29 999	10 (13.9)	3 (5.6)	—
$30 000 - $44 999	17 (23.6)	11 (20.8)	—
$45 000 - $59 999	9 (12.5)	10 (18.9)	—
$60 000 - $74 999	8 (11.1)	3 (5.6)	—
>$75 000	9 (12.5)	6 (11.3)	—
Prefer not to answer	14 (19.4)	15 (28.3)	—
Mean hours of work/volunteering per week	21.00 ± 13.11	14.22±10.06	0.075
Mean years providing care to care recipient	6.4 ± 1.2	13.4±5.8	0.015[b]
Mean hours of care provided per week	41.7 ± 18.40	38.4±16.58	0.514[b]
Provides care to more than one person	21 (29.2)	13 (24.5)	0.207[b]
Lives with care recipient	53 (73.6)	39 (73.6)	0.002
Caregiver type			
Spouse/common law partner	37 (51.4)	32 (60.4)	0.001
Child	23 (31.9)	6 (11.3)	—
Parent	2 (2.8)	6 (11.3)	—
Mean age of care recipient [SD]	74.6 [12.2]	67.1 [17.6]	0.037[b]
Sex of care recipient			
Female	39 (54.2)	27 (50.9)	0.001
Care recipient receives formal (paid) care	29 (40.3)	17 (32.1)	0.001

[a] Kruskal Wallis.
[b] t-test.

while the meal container was least preferred (rank score = 305).

Inter-group analyses

The choices of participants based on the group they belonged to in terms of caregiving in the context of NCD are shown in Figures 2 and 3. The numbers on the charts represent the mean rank score calculated for each potential technological solution.

The preferences of caregivers of people with NCD displayed in Figure 2 were different from those providing care to people with non-NCD related disability (Figure 3). For example, the smart braking system for walking aid devices was ranked higher by NCD caregivers than non-NCD caregivers. The biggest difference between the two groups is also about the preference for the smart braking system for walking aid devices, which was in the 9th position for the non-NCD group ranking. While the rankings of other solutions did not show such large differences, there are some variations between groups that are worth pointing out. All the web-based solutions were ranked in the first four positions by the non-NCD group. In addition, having a personalized cab service and posture monitoring device were more preferred by non- NCD caregivers.

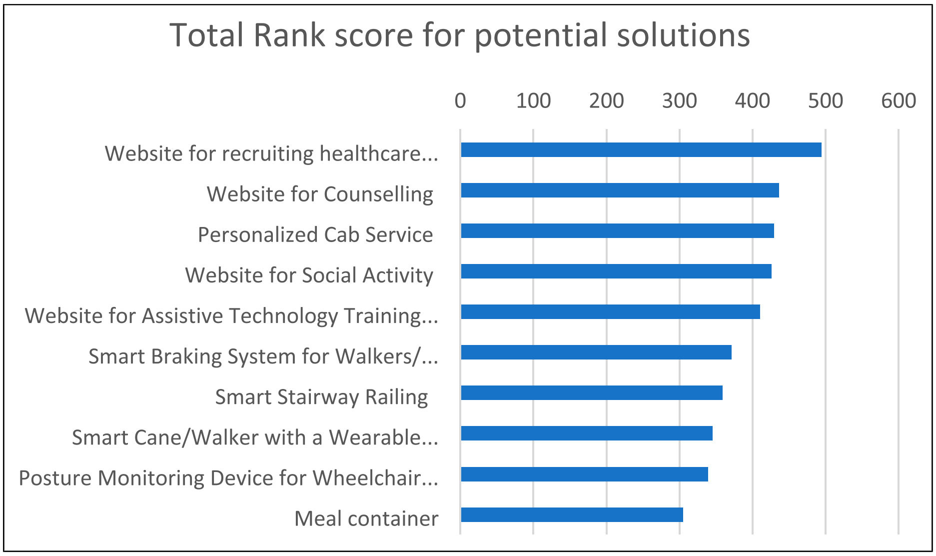

Figure 1. Preferences of all participants (numbers on chart represent rank score (rs) (*n* = 3914).

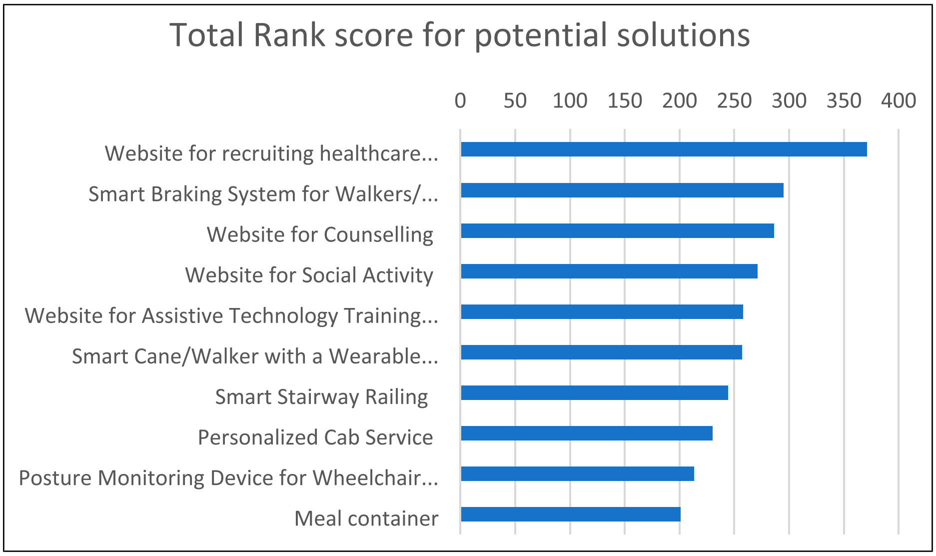

Figure 2. Preferences of participants in the NCD group (*n* = 2626).

Eight of the solutions were ranked differently by caregivers in different groups. Two of the potential solutions (personalized cab service for transportation and posture monitoring device for wheelchair users) differ in position between the two groups by three places and two (website for social activity, website for AT training, and smart cane/walker with a wearable bracelet) differ in position by two places between both groups.

Discussion

This human-centered design study explored preferences of informal caregivers of people living with NCD in terms of the technological solutions they are seeking to help make caregiving easier. The preferences of participants providing care to people living with NCD were also compared to those of caregivers caring for people with other conditions that are not NCD.

Overall, caregivers seemed to desire web-based solutions as these were among the first five choices for participants when all preferences were considered regardless of their context of care group. Caregivers' preferences for web-based solutions may be due to the ease of using apps and web pages for planning and completing tasks without having to be physically present as well as the potential for

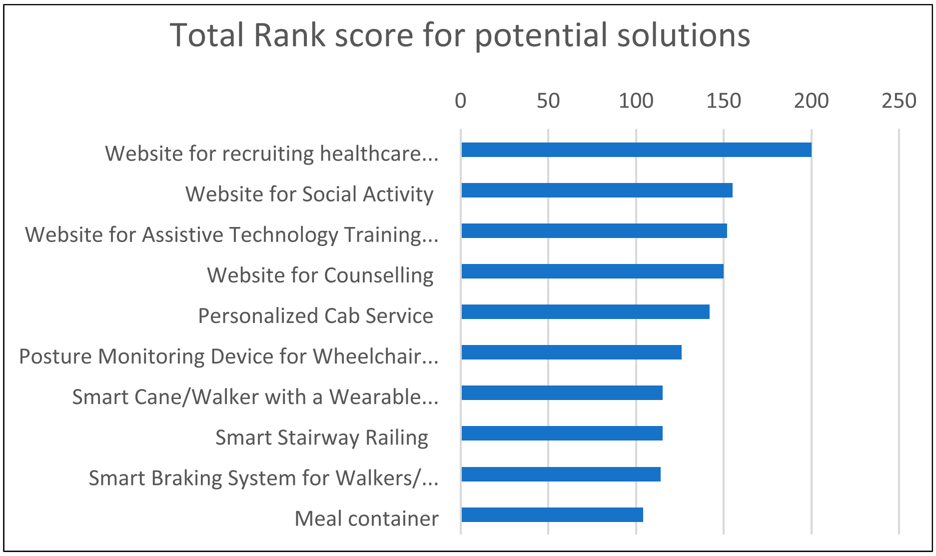

Figure 3. Preferences of participants in the non-NCD group (*n* = 1373).

asynchronous access to these resources on their own schedule. For instance, web-based applications can be used anytime for counselling and scheduling or completing appointments.[28] In addition, websites and applications have the potential to reduce waiting times, eliminate the need for transportation and reduce cost (transport/parking) to the care-recipient.[29]

Considering the ranking of solutions by group, the technology preferences of caregivers varied based on how useful they were perceived for their specific situations. Differences in preferences between the NCD and non-NCD groups may also reflect their unmet needs. People who have challenges with their cognitive abilities as seen in most NCD may have greater need for smart devices. Caregivers of people with NCD on average were more interested in solutions that would allow them to be more independent as they access services or carry out their normal day to day activities even if they had cognitive or memory impairment. The loss of cognitive abilities associated with NCD might be responsible for the preference for web-based solutions and smart systems among caregivers of people with NCD. This finding is consistent with prior research results that suggested daily function and self-efficacy regarding ability to manage memory impairment were of utmost importance to patients living with NCD.[30] The relatively higher ranking of a posture monitoring device by caregivers of people with non-NCD-related disabilities may be a pointer to the need for a solution that could help in physical disability situations. Likewise, affinity for mobility-related solutions among caregivers in this group reflect preferences that would help provide support for people who provide care in the context of physical disability. Having access to solutions that make transport and appropriate paid care more accessible to people with physical disabilities have been shown to provide relief to their informal caregivers and offer users a better quality of life.[31,32]

Generally, caregiver's preferences for potential solutions mirrored certain needs that are generally influenced by the degree of help required. Research has shown that the level of impairment or stage of disease of the care recipient is a determinant of their level of healthcare and caregiving needs.[33,34] Different types of AT tend to have varying effects contingent on indications for them and how well the user is able to maneuver them for their functional benefits. For instance, depending on functional status, canes are preferred to crutches in maintaining gait stability as the latter may be regarded as cumbersome and are increasingly out of favor by some users.[35] Similarly, the website for AT training for caregivers and users meant more to those in the NCD group probably because they need specific and simplified instructions to guide their use of assistive devices. In addition, some of the potential solutions may be more focused on people with specific needs or have a broader appeal because the pertain to larger number of caregivers. For example, only wheelchair users would have a need for the posture monitoring device on wheelchairs.[36] Thus, the ranking of such technology might be restricted to those who require it. While 'niche' solutions are quite important and may be particularly preferred by those who need them, they might not have been ranked higher by the general cohorts of participants. Furthermore, it is unclear what informed caregivers' ranking decisions, whether they might have ranked devices based on their perceived impact generally or for themselves and their care recipients specifically. Therefore, it is difficult to adopt a 'one size fits all' approach to developing solutions for informal caregivers and the people they care for.[37,38] It is pertinent to continue to involve caregivers in conversations about their technology needs and how they would like to address them in a human-centered design context.

The relatively lower ranking of the website for social activity by caregivers of people with NCD is surprising, as previous studies have found that one of the unmet needs of informal caregivers often is to find social support and understanding by others[39] and caregivers often desire to interact and share ideas with their peers.[31] However, this may reflect a perception that socialization is considered less essential than care recipients' basic activities of daily living. Nevertheless, the ranking of each item based on how they were rated by survey participants is relative and should be interpreted with care. The survey questions asked participants to rate solutions based on how important they considered them. Although caregivers may rate a solution higher than others, it is likely that they would still find the other solutions useful.

Limitations

This study has some limitations. First, the participants recruited through convenient sampling are not representative of the entire population of Canadian informal caregivers. Notwithstanding the sampling technique, the participants were able to access the survey and provided valuable information for analysis to provide context for this research. Our ranking was based on how important participants considered each solution and this helped confirm choices in situations where solutions may have equal importance. Second, our use of preferences as an indicator of care intentions is to an extent, subjective. However, questions about intentions have been proven to be very simple and efficient to predict health related behaviour. The assessment of preferences of caregivers provides basis for analyzing and comparing preferred technological solutions.

Conclusion

We surveyed caregivers about their preferences regarding potential technological solution and compared the preferences of those providing care to people with NCD with those who are not. Our findings suggest that in both groups caregivers generally prefer web-based solutions. Although some potential solutions were ranked higher than others, the less preferred ones are not necessarily unwanted but may have less broad appeal. Further research could focus on identifying the reasons why caregivers and care recipients prefer specific solutions and contextualize how such could help relieve caregiving burden.

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Guarantor

OA.

Contributorship

WBM, FR and OA researched literature and conceived the study. All authors were involved in protocol development, gaining ethical approval, patient recruitment and data analysis. OA wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

ORCID iDs

Oladele Atoyebi https://orcid.org/0000-0001-9541-0894
François Routhier https://orcid.org/0000-0002-5458-6233

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