
JMIR Aging

Journal Impact Factor (JIF) (2022): 4.9

Volume 1 (2018), Issue 1 ISSN 2561-7605 Editor in Chief: Yun Jiang, PhD, MS, RN, FAMIA; Jinjiao Wang, PhD, RN, MPhil

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Original Paper

A Web-Based Intervention to Help Caregivers of Older Adults With Dementia and Multiple Chronic Conditions: Qualitative Study

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Abstract

Background: Caregivers (ie, family members and friends) play a vital role in the ongoing care and well-being of community-living older persons with Alzheimer disease and related dementia in combination with multiple chronic conditions. However, they often do so to the detriment of their own physical, mental, and emotional health. Caregivers often experience multiple challenges in their caregiving roles and responsibilities. Recent evidence suggests that Web-based interventions have the potential to support caregivers by decreasing caregiver stress and burden. However, we know little about how Web-based supports help caregivers.

Objective: The objectives of this paper were to describe (1) how the use of a self-administered, psychosocial, supportive, Web-based Transition Toolkit, My Tools 4 Care (MT4C), designed by atmist, Edmonton, Alberta, Canada, helped caregivers of older adults with Alzheimer disease and related dementia and multiple chronic conditions; (2) which features of MT4C caregivers found most and least beneficial; and (3) what changes would they would recommend making to MT4C.

Methods: This study was part of a larger multisite mixed-methods pragmatic randomized controlled trial. The qualitative portion of the study and the focus of this paper used a qualitative descriptive design. Data collectors conducted semistructured, open-ended, telephone interviews with study participants who were randomly allocated to use MT4C for 3 months. All interviews were audio-taped and ranged from 20 to 40 min. Interviews were conducted at 1 and 3 months following a baseline interview. Qualitative content analysis was used to analyze collected data.

Results: Fifty-six caregivers from Alberta and Ontario, Canada, participated in either one or both of the follow-up interviews (89 interviews in total). Caregivers explained that using MT4C (1) encouraged reflection; (2) encouraged sharing of caregiving experiences; (3) provided a source of information and education; (4) provided affirmation; and for some participants (5) did not help. Caregivers also described features of MT4C that they found most and least beneficial and changes they would recommend making to MT4C.

Conclusions: Study results indicate that a self-administered psychosocial supportive Web-based resource helps caregivers of community-dwelling older adults with Alzheimer disease and related dementia and multiple chronic conditions with their complex caregiving roles and responsibilities. The use of MT4C also helped caregivers in identifying supports for caring, caring for self, and planning for future caregiving roles and responsibilities. Caregivers shared important recommendations for future development of Web-based supports.

(*JMIR Aging 2018;1(1):e2*) doi:[10.2196/aging.8475](https://doi.org/10.2196/aging.8475)

KEYWORDS

Internet; Web-based interventions; qualitative research; caregivers; aged; dementia; multiple chronic conditions

Introduction

Background

For the majority of older persons living at home with Alzheimer disease and related dementias (ADRD), family and friends take on the role of caregivers [1,2]. The trajectory of caring for a person with ADRD is typically a long process that evolves over time and intensifies, becoming more time-consuming as well as physically and emotionally demanding as the disease progresses [1]. This care is made even more complex by the presence of multiple chronic conditions (MCC), defined as 2 or more concurrent chronic conditions. A recent retrospective cohort study of community-living older adults in Ontario, Canada, found that 83% of people with dementia had 2 or more chronic conditions [3], which is even higher than people with diabetes, 76% of whom have 2 or more chronic conditions [4]. In a recent study that involved caregivers of community-living older adults with 3 or more chronic conditions, with at least one of dementia, diabetes, or stroke, the experience of managing MCC was described by caregivers as a complex, overwhelming, draining, and complicated process [5]. While caring for a person with ADRD can provide a source of meaning and fulfillment [1], its adverse effects on the caregiver's physical and mental health, financial well-being, and quality of life are well documented [6-9]. Effective, innovative and cost-efficient interventions are needed to address the deleterious effects of caregiving and to support caregivers in caring for persons with ADRD and MCC. Web-based interventions offer a potentially low-cost and accessible way to help these caregivers.

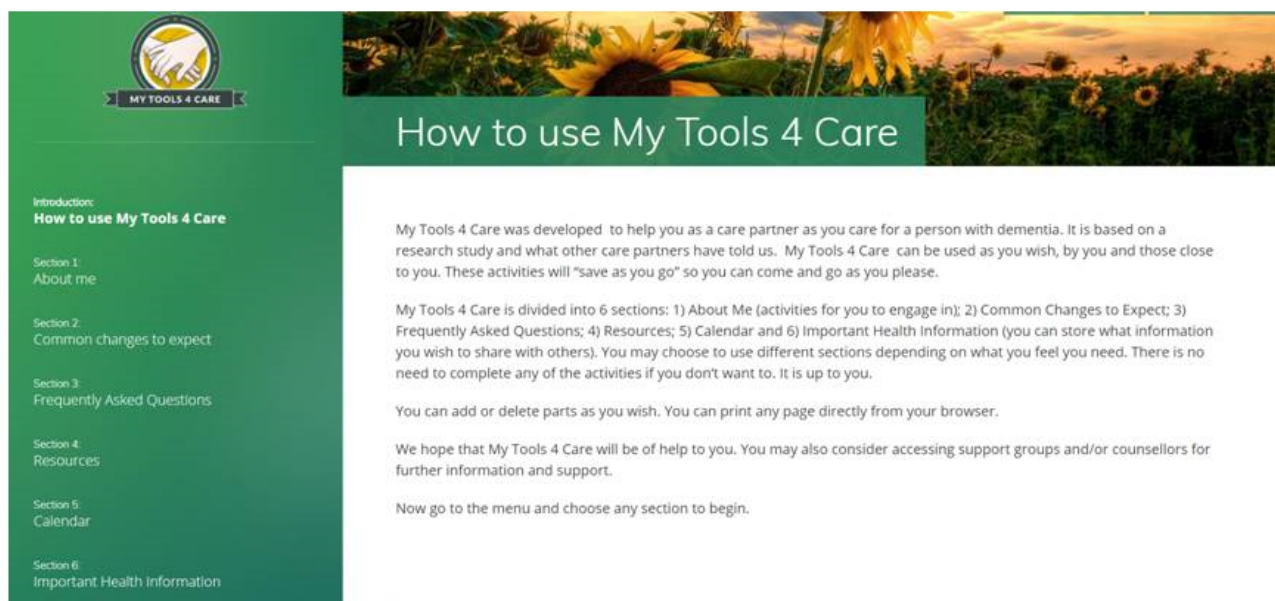
Use of Web-Based Resources Among Caregivers

There is growing evidence that Web-based interventions are cost-effective, efficient, and offer the potential of greater accessibility to caregivers [10]. Caregivers of persons with dementia may favor Web-based tools over face-to-face meetings because of lack of time; concerns with privacy; the need to travel, leave, or arrange care; and stigma [11]. A number of

recent systematic reviews have examined the characteristics and effectiveness of Web-based interventions for caregivers of community-dwelling people living with dementia [12-16]. The components and delivery of the interventions are heterogeneous, ranging from websites with information and support to a combination of information with email, support by a coach, or exchange with other caregivers online [12]. Web-based interventions have positive effects on the well-being of caregivers, such as reductions in stress, burden, and depression [12,14]. Caregivers who used Web-based interventions reported increased confidence and self-efficacy in caregiving [12,14]. A recent systematic review examined social support interventions, including Web-based supports, for caregivers of persons with dementia [13]. Qualitative findings revealed that Web-based social interventions allowed for sharing and companionship and reduced social isolation and improved relationship quality with the person with ADRD [13].

Some studies have reported qualitative findings on caregivers' experiences in using Web-based tools and have revealed that caregivers valued the convenience and flexibility of these tools [17-21]. Many caregivers gained knowledge and skills and learned strategies that helped them care for the person with dementia [17,19,20,22]. Some studies cited the opportunity to interact and share with, and learn from other caregivers (ie, via email, online discussion groups, blogs, or video meetings) as a benefit to the Web-based intervention [20,22]. Caregivers appreciated (1) being able to discuss their situation and express themselves freely [18,21,23]; (2) hearing the stories of other caregivers [22,23], and (3) receiving support from other caregivers [20]. Another frequently cited benefit of Web-based interventions was the opportunity to access caregiving support and advice from professionals [18,21-23].

Conversely, caregivers identified aspects of Web-based interventions that were not beneficial. These included (1) a lack of, or limited interaction with, other caregivers [18-20]; (2) difficulty with language and computer literacy [23]; and (3) difficulty with navigation [19] or specific aspects of the website.

Figure 1. Screenshot of MyTools4Care.

We know little from a qualitative perspective of caregivers' experiences with using Web-based interventions and how the use of these supports helps caregivers. This study is important in providing in-depth qualitative insight into how a psychosocial, Web-based intervention may help caregivers in caring for persons living with ADRD and MCC. Recommendations made by caregivers will be valuable in shaping the development of future Web-based interventions.

Description of Intervention: My Tools 4 Care

This study is part of a larger multisite, pragmatic, mixed methods randomized controlled trial (RCT) [24]. The purpose of the RCT was to determine how the use of a self-administered, psychosocial, supportive, Web-based Transition Toolkit, My Tools 4 Care (MT4C), designed by atmist, Edmonton, Alberta, Canada, affects health-related quality of life, hope, and self-efficacy among caregivers of older adults (≥ 65 years) with ADRD and MCC compared with an educational control group. The Transition Toolkit developed by Duggleby, Swindle, and Peacock [25], was based on transitions theory [26].

The original paper-based Transition Toolkit was assessed in a pilot study and found to be feasible, easy to use, acceptable for use, and to have the potential to support caregivers through transitions [25]. On the basis of the pilot study, it was converted into a Web-based format: MT4C. MT4C consists of 6 sections: About Me, Common Changes to Expect, Frequently Asked Questions, Resources, Important Health Information, and a Calendar (see Figure 1). MT4C is self-administered and designed to be used by the caregiver when and how they wish. In the About Me section, users have the option to add content, such as their personal thoughts or reflections about their story and goals as a caregiver, and to store or upload information about themselves or the care recipient. The site offers information about changes that caregivers may experience, answers to frequently asked questions, weblinks to information and resources, and links to videos and written comments that capture the experiences of other caregivers. A detailed

description of the sections and content of the Transition Toolkit is available in the protocol paper [24].

Research Questions

This paper reports on the qualitative findings from participants who were randomly assigned to use MT4C for 3 months as part of the larger RCT. The research questions for the qualitative portion of the study were as follows:

1. How does a self-administered psychosocial, Web-based Transition Toolkit (MT4C) help caregivers of community-dwelling older adults with ADRD and MCC?
2. Which features of the Toolkit do caregivers find most and least helpful?
3. What changes would caregivers recommend making to the Toolkit?

Methods

Study Design

A qualitative descriptive design was used [27,28]. Qualitative description is based on the theoretical foundation of naturalistic inquiry, which aims to study events and persons in their natural state. The methodology aims to provide an accurate description of the phenomenon using everyday language.

Sample

Consistent with the qualitative descriptive approach, a combination of criterion and maximum variation sampling techniques were used to obtain a purposeful sample ($N=56$) of caregivers of older adults with ADRD and MCC who were living at home, across both study sites (Alberta and Ontario, Canada). Unpaid caregivers who met the following criteria were eligible to participate in the larger RCT and included (1) a family member or friend who was providing physical, emotional, or financial care to an older adult (≥ 65 years of age) who had ADRD and 2 or more chronic conditions and was living at home; (2) English-speaking; (3) ≥ 18 years of age; and (4) able to use and had access to a computer with internet connection and had

an email address. We used maximum variation sampling to achieve a broad representation of caregivers by gender, relationship with the care recipient (eg, spouse, child, other), and province.

Recruitment

For the RCT, eligible participants were primarily recruited through local branches of the Alzheimer Society in both provinces. Site-specific research staff attended caregiver education groups or events held by the Alzheimer Society, to share information about the study and recruit potential participants. Coordinators from other community-based caregiver support groups, geriatric outpatient or memory clinics, adult day programs, and senior support services assisted in distributing recruitment materials (eg, brochures or postcards) to interested caregivers and referred them to the appropriate research staff in each site. With their consent, interested caregivers were contacted by the research coordinator to answer their questions, confirm their eligibility to participate in the study, and arrange a time for the first interview.

Data Collection

From June 2015 to October 2016, data collectors conducted semistructured, open-ended telephone interviews with study participants. All interviews were audio-taped and ranged from 20 to 40 min. Interviews were conducted at 1 and 3 months following the baseline interview. The 1-month interview captured participants' early response to MT4C, while the 3-month interview captured their response just as their access to MT4C ended. Building on the earlier work of Duggleby and colleagues [25,29], a qualitative interview guide was developed to ask participants to describe (1) how the use of MT4C helped them; (2) the features of MT4C that they found most and least helpful; and (3) what changes they would recommend making to the Toolkit (see [Textbox 1](#)).

There were 3 data collectors in Ontario and 2 in Alberta. Data collectors were health care providers and trainees and received training in conducting qualitative interviews from the project leads before they began data collection. Project leads reviewed selected interview transcripts throughout the data collection period to ensure that questions and probes were used appropriately and that data collectors were able to engage caregivers in discussion and obtain rich information. The average duration of interviews was similar across data collectors.

Data Analysis

All interviews were transcribed verbatim by an experienced transcriptionist and then cleaned by a research assistant. Analysis

was completed by a subgroup (n=4) of the larger research team. Consistent with a qualitative descriptive design, qualitative content analysis was used to analyze the data [27,28]. We used a conventional content analysis approach where coding categories were derived directly from the text data [30]. The research questions provided a broad frame for the categorization of the data. Initially, all 4 members of the analysis team independently read each transcript, looking for similarities, differences and patterns in the data, and labeling them with codes [31]. Members then met regularly to discuss, compare, corroborate, and revise codes and group them into themes describing the caregiver's experience. NVivo 11 software (QSR International Inc., Burlington, MA) was used to manage and support analysis of the study data.

Several strategies were used to enhance the rigor of the study and ultimately produce an accurate description of the experience of using MT4C among caregivers of older adults with ADRD and MCC. Credibility, or the accuracy of the description of the caregivers' experiences, was enhanced by purposefully sampling caregivers of community-living older adults with ADRD and MCC.

Conducting semistructured individual telephone interviews with caregivers at 1 and 3 months helped to establish trust between the interviewer and the interviewee and provided participants the opportunity to discuss their experiences from their own perspectives. Data collectors' written field notes from each interview helped them to recall participants' characteristics, understand the context of the interview, and follow up on the information that caregivers provided. The transcription of each recorded interview ensured that participants' words and perspectives were represented accurately. Meeting frequently as a team to review data coding and analysis as well as maintaining a coding journal ensured that codes remained data driven and that decisions related to analysis were tracked.

Ethics

The study was approved by the Hamilton Integrated Research Ethics Board in Hamilton, Ontario (#15-309) and by the Health Research Ethics Board—Health Panel at the University of Alberta (Pro000048721) in Edmonton, Alberta. Trained, site-specific data collectors obtained participants' informed verbal consent before each telephone interview. A copy of the study information and consent form was sent by email to each participant immediately following the baseline interview.

Textbox 1. Interview guide for qualitative interviews with caregivers allocated to use My Tools 4 Care (MT4C) at 1 and 3 months post baseline.

1. Describe any significant changes you experienced as a caregiver in the past 3 months.
2. What were you thinking about when you worked on My Tools 4 Care?
3. Did it help you deal with significant changes you experienced as a caregiver? Why or why not?
4. Did anything influence your ability to work on My Tools 4 Care?
5. Who do you think would benefit most from My Tools 4 Care?
6. What did you like best? What did you like least?
7. Do you have any other suggestions or anything else to add?

Results

Caregivers' Demographic Characteristics

Fifty-six caregivers completed at least 1 semistructured telephone interview; 44 one-month interviews and 45 three-month interviews were completed. Caregivers ranged in age from 22 to 91 years, with a mean age of 64 years (SD 13) at the baseline interview. Most caregivers were female (77%, 43/56), married (84%, 47/56), and reported having medical conditions (79%, 44/56; see Table 1). While over half of these caregivers (55%, 31/56) were the spouse of the person with ADRD and MCC, a large proportion of participants were children of the care recipient (39%, 22/56). Most caregivers (77%, 43/56) lived with the person with ADRD and MCC for whom they provided care, and most (70%, 39/56) reported receiving some assistance with caregiving that is, informal (family) or formal (home care) support. Half of the study participants had been providing care for 3 or more years (50%, 28/56), whereas the other half had been in their caregiving role for 2 years or less (50%, 28/56).

Care recipients ranged from 65 to 95 years of age, with a mean age of 80 years (SD 8). Care recipients had between 2 and 17 (mean=9, SD 4) chronic conditions, in addition to ADRD. The most commonly reported chronic conditions were bowel or bladder incontinence (63%, 35/56); hypertension (59%, 33/56); arthritis, and osteoarthritis or osteoporosis (57%, 32/56).

Qualitative Findings

Caregivers explained that using MT4C (1) encouraged reflection; (2) encouraged sharing of caregiving experiences; (3) provided a source of information and education; (4) provided affirmation; and for some participants (5) did not help. Illustrative quotes have been labeled with the participant number and the time of the interview (ie, M1=Month 1 or M3=Month 3, accordingly).

Using My Tools 4 Care Encouraged Reflection

Participants who used MT4C noted that many of the activities in About Me (Section 1 of the Toolkit); which included My Story, What Helps Me?, My Goals as a Care Partner, What is My Back-up Plan?, Everyday Hope, and What am I Doing for Myself Today?, encouraged them to reflect on their experience as a caregiver:

...you can type down something, type it in, and then it's almost like a diary. And then kind of go back and go, "Hmm, I wonder, why did I put it that way?" [Participant 322, M1]

Participants noted that taking time to reflect on their experience was important in dealing with caregiving demands but seldom done:

It [MT4C] allowed me to write down stuff that I haven't stopped to write down, and I found that that was very helpful...just the opportunity to write down my story and how things have gone. It's not something a caregiver takes time to do, and it's really

important...It makes you think of stuff that you sort of put in the back of your brain and it makes you put it down in front of you. [Participant 1, M1]

The act of reflecting on their experience gave participants an opportunity to analyze their caregiving roles and tasks and assess what changes they needed to make in their thinking or actions related to caregiving:

...it made me take a deeper, inner look at myself, which I seldom do because I'm more focusing on [name of spouse] than I am on myself, and I've always found it a little difficult to focus on myself anyhow...it gave me a little chance of soul-searching and analyzing what I am doing, and assessing some of the things I need to revise in my own thinking. So I found it very challenging and interesting. [Participant 301, M1]

Using My Tools 4 Care Encouraged Sharing of Caregiving Experiences

Participants described how MT4C provided the opportunity to write down their thoughts and share their experiences as a caregiver. For example, caregivers appreciated telling their story, explaining their goals as a care partner, or considering their backup plan. Some caregivers described how MT4C helped them cope with their emotions by allowing them to write about their experiences:

I just found it more, therapeutic, I think, than anything else, to write down those things that I needed to think about. [Participant 383, M1]

This was particularly true during stressful situations when other support was not present, as described by one caregiver:

Well, the writing down of the stressful things that were happening; just the fact that I was able to share things and not keep it to myself, kind of thing. As I say, when all this happens, I'm on my own, and just the fact that I can share it is, you know, even if nobody reads it, the fact that I've took it out of my mind, there. So I did really find that helpful. [Participant 330, M3]

Other caregivers described how MT4C prompted them to be mindful of things that help them get through the day and reinforced the importance of self-care. As the following caregivers stated:

I did do some of the ones [sections of the website] of taking care of myself and...that's one of my big things is that I understand that I really have to take care of myself, because I can't help [name of spouse] if I'm not well. [Participant 337, M1]

...the place where you had to make a list of the things that help you get through the day, [What Helps Me?] because I think it is such a negative situation and it's so exhausting, physically and mentally and emotionally, that you could forget about that. So in the sense that it made you sit and think about it, I think that was a positive thing. [Participant 349, M3]

Table 1. Caregivers' baseline demographic characteristics (Alberta and Ontario, N=56).

Demographic characteristics	n (%)
Gender	
Male	13 (23)
Female	43 (77)
Marital status	
Married	47 (84)
Single	5 (9)
Divorced/separated	3 (5)
Common Law	1 (2)
Ethnicity	
White	50 (89)
Other	6 (11)
Nationality	
Canadian citizen	54 (96)
Landed immigrant	2 (4)
Employed	
Yes	20 (36)
No	36 (64)
Employment status (if employed outside the home)	
Full-time	9 (16)
Casual/part-time	4 (7)
Not applicable	43 (77)
Self-employed	
Yes	7 (13)
No	13 (23)
Not applicable	36 (64)
Relationship to care receiver	
Spouse/partner	31 (55)
Son/daughter	22 (39)
Daughter-in-law	2 (4)
Grand-daughter	1 (2)
Number of years caring for care recipient^a	
<1 year	14 (25)
1-2 years	14 (25)
3-5 years	15 (27)
6-10 years	10 (18)
>10 years	3 (5)
Living with care recipient	
Yes	43 (77)
No	13 (23)
If yes, type of residence (n=43)	
Own home/condo	35 (81)
Rent home/apartment	7 (16)

Demographic characteristics	n (%)
Retirement or assisted living	1 (2)
Receive assistance with caregiving	
Yes	39 (70)
No	17 (30)
Caregiver has medical conditions	
Yes	44 (79)
No	12 (21)
Estimated annual household income before taxes (\$ CAD)	
\$10,000-\$29,999	8 (14)
\$30,000-\$49,999	14 (25)
\$50,000-\$69,999	9 (16)
Greater than \$70,000	19 (34)
No answer	6 (11)
Finances meet needs	
Completely	7 (13)
Very well	12 (21)
Adequately	26 (46)
With some difficulty	8 (14)
Not very well/totally inadequately	3 (5)

^aAs of June 1, 2015.

For some caregivers, using MT4C encouraged them to:

...look at what's coming and plan for the future.
[Participant 372, M3]

Often, this meant anticipating and planning for the upcoming care needs of the care recipient:

...But the long-term is what made me think...my husband and myself manage all her medical things, and it [MT4C] made me even realize somebody else needs a list of doctors and [chuckles] you know, things like that...It made me think about personal care in the future because that's long-term care.
[Participant 344, M1]

Participants also talked about anticipating and planning for changes such as the care recipient's move to assisted living or long-term care; arranging power of attorney; and anticipating changes to their living arrangements, such as making modifications to their existing home to accommodate the needs of the care recipient, or moving to be closer to family and other forms of support.

Using My Tools 4 Care Provided a Source of Information and Education

Caregivers described how MT4C provided them with information or direction on how to find information, for example, about changes to the caregiver's roles and relationships, environment, physical and mental health, daily activities, and the need for support (Section 2, Common Changes to Expect); how to access services and find information

(Frequently Asked Questions, Section 3); and other helpful resources (Section 4, Resources). One participant described MT4C as a reference:

...something I could look at and use part of it or some of it, a little of it or none of it, but it gave me that basis to...sort of a mode of attack of how I was going to handle the situation. [Participant 301, M3]

Participants who used MT4C appreciated that it provided useful, timely and new information that helped them to understand and deal with the disease-related changes in the care recipient:

...And even though I did do a lot of research, some of the stuff in there I hadn't found before, so it helped me. [Participant 11, M1]

The information about dementia helped caregivers assess the current stage of dementia and plan for what was to come:

And it [MT4C] gives you the information and very detailed description of each level of, where they're at in their dementia process. I found that was much better than what other sites that I've read...so I was better able to reassess where I thought my husband was at, compared to other sites where I've used essentially the same sort of tool, but not worded in such a way that was really as helpful as it is on your site. [Participant 1, M1]

Participants found the links to resources within MT4C particularly helpful in supplying specific information that was relevant to planning for taking on new roles:

I like the fact that you give out the telephone numbers and the contact information, national contacts, I think that's great! That's information worth something to me. [Participant 365, M3]

Participants explained that the links to resources, for example information about Power of Attorney, helped them to plan for taking on new roles as caregivers, such as managing financial and health care decisions:

The Resources, that one meant more to me than anything else, that's probably where I spent most of the time, the links to the legal stuff, I needed that because I wanted to find out about Powers of Attorney. [Participant 350, M3]

Using My Tools 4 Care Provided Affirmation

Participants described how their use of MT4C provided affirmation that their experiences were comparable to those of other caregivers, that they were not alone in their journeys. Using MT4C provided confirmation that they were doing the best they could in their caregiving roles. This affirmation helped give them the courage to deal with ongoing changes such as taking on new roles and responsibilities as the health of their loved one deteriorated, dealing with increased social isolation, and planning for possible placement. Participants found the examples of transitions experienced by other caregivers available on MT4C (in text or video format) provided:

...confirmation that you're not alone. [Participant 345, M1]

Participants repeatedly stated that these written experiences decreased their feelings of isolation and that it was reassuring to know that other caregivers were going through the same situations and feelings.

It's nice seeing comments from other people, and there should be a lot more of that. Because you end up thinking—and I know it's not the case—but you end up thinking that you're the only one going through it, and then you realize that there's an awful lot of other people doing it, too. [Participant 21, M3]

Because dementia caregiving is different for every caregiver and every person with dementia, it was often difficult for caregivers to know if they were using the right caregiving strategies and approaches to care, or if they were making the best decisions for the person with dementia. Caregivers verbalized that MT4C provided a sense of validation that they were providing good care:

Well, basically, [the website validated] that I'm doing the right things, and that I'm providing good care. I'm providing for her comforts and making her quality of life as good as it can possibly be under the circumstances. And that's [been] my objectives. You know, longevity versus quality [of life]. [Participant 23, M3]

Caregivers noted that using MT4C reaffirmed the normality of the caregiving journey. Participants felt reassured that their experiences were “normal”:

It's what's to be expected, and not anything we didn't do, or that we're doing wrong, or, that we haven't done. [Participant 390, M1]

One caregiver used MT4C to validate their caregiving approaches and journey:

In each of the sections, I've well been there. I've been caregiving since 2008, and I have a large care manual that I started writing, and I've accumulated a lot of information...So you know, I have my objectives and I have long-term plans of certain things I'm going to do. So when I look at the website, I think I'm pretty well on track. [Participant 23, M1]

Using My Tools 4 Care Did Not Help

Some participants indicated that using MT4C did not help them because (1) they were meeting or had already met their caregiving needs by other means, (2) they felt that it was not the right time to use MT4C, or (3) they did not have time to use MT4C. Many participants in this study were experienced caregivers; 50% had been caregiving for 3 or more years. Therefore, many had long established strategies in place to help meet their caregiving needs. These were often cited as reasons for not using parts of MT4C. For example, several participants indicated that they were already familiar with available resources and had already used or were using community-based services to answer their questions and address their caregiving concerns. As one participant explained:

It [MT4C] didn't help me significantly...I had gone to some caregivers' group and got some information there. [Participant 24, M3]

Many caregivers had contacted a local branch of the Alzheimer Society in the past or were currently connected with the organization and attending various education or support groups or obtaining more immediate advice by phone:

I've been extremely reliant on the Alzheimer Society...and I've found them to be very good with their information and their support...I think most of the time...we have something already in place. [Participant 308, M3]

In some cases, participants felt that they didn't really need MT4C or that the information provided in MT4C did not apply to their current situation, indicating that it was either too early or too late in their dementia journey to use MT4C. This is evident from the following statements:

...didn't really need it [MT4C] at this point. [Participant 379, M3]

I feel like I'm not there yet; Mom's still early, so some of the things are a bit more advanced, talking about getting help and that sort of thing. We aren't at that stage yet so I could see maybe as things progress that maybe I'd be going back here to kind of have it as another resource. I think that's probably the main thing, is I feel like I don't need it yet. [Participant 345, M1]

One caregiver who had been caring for her 89-year-old mother for almost 4 years expressed how she felt that the Toolkit could not help her because:

I've figured out everything on my own. [Participant 35, M1]

The same participant stated:

...I'm at the end now. And for somebody new into the dementia journey, I think it's a great tool...right now, because I'm emotionally wrecked, physically, financially it [MT4C] can't help me now [laughs]. [Participant 35, M3]

Features of My Tools 4 Care Found to Be Most and Least Helpful

Caregivers found the layout of MT4C to be “very well organized” [Participant 342, M3], easy to navigate, and easy to use. They also found it was helpful to (1) have the opportunity to reflect on and to share their caregiving experiences (in writing); (2) receive information that was relevant and applicable to their situation; and (3) obtain validation of their caregiving experiences through the content of the website and linked videos. Aspects of the Toolkit that some participants found were least beneficial included (1) the Toolkit did not apply to the caregiver’s current situation or suit their current needs because of their stage in the caregiving journey; (2) challenges with technology and security concerns; (3) writing or sharing their thoughts and experiences in MT4C; and (4) lack of time to use the site due to the demands of caregiving and other responsibilities. As one caregiver explained:

The amount of time you had to sit and write things down, type things in, and to be honest with you, the more time I spend on the computer, the more [name of spouse] approaches me and saying “What are you doing? Why aren't you sitting with me?” [Participant 353, M3]

Caregivers' Recommendations to Improve My Tools 4 Care

Participants offered a number of recommendations to improve the content and format of the Toolkit and other Web-based resources for caregivers. Suggestions for guidance and information about local resources and how to access them were commonly expressed by participants. To meet these needs, caregivers suggested (1) adding a directory of services that is searchable by postal code, (2) having a person available to answer caregivers’ questions by telephone, and (3) having a navigator to “be that bridge” [Participant 373, M3] to help the caregiver identify and access resources that meet their specific needs.

Participants also requested practical caregiving tips and strategies to help them manage the daily challenges they face as caregivers of older adults with ADRD and MCC and particularly valued receiving this information from other caregivers. Some participants commented that adding a feature to MT4C to enable caregivers to connect with one another to share information, experiences, and caregiving strategies would be helpful:

...if you connect with people over the internet say, you know, I'm having a really hard time today and somebody can say: “I know what you're going through,” that can be good support too, you know? [Participant 399, M3]

Some caregivers suggested improvements to make MT4C more user-friendly. These included reducing the use of medical language and adjusting literacy levels and providing an overview of the content of the site. As one participant stated:

...it is a lot of text, and the literacy level. Oh, the other thing is it's only in English...you need to make the language a bit simpler. [Participant 331, M3]

Discussion

Principal Findings

This is the first known study to examine how a Web-based intervention helps caregivers of community-dwelling older adults with ADRD and MCC. Caregivers indicated that using MT4C encouraged reflection, helped them to share their caregiving experiences, provided information and resources and affirmed their caregiving roles. This, in turn, helped them to deal with caregiving demands such as taking on more roles and responsibilities as their loved one’s health and abilities declined; coping with increasing social isolation; caring for self as their own health declined, and planning for future caregiving changes such as arranging alternate living arrangements.

MT4C served as a confidential outlet that provided participants a rare opportunity to tell their stories and to reflect on their caregiving experiences through writing. Caregivers were prompted to think about aspects of caregiving that they had not considered before, including their own health and well-being and the importance of self-care. In some cases, the act of reflecting on and writing about their experiences resulted in new insight that helped to reduce caregivers’ stress and helped them to cope with the challenges and emotions associated with their role. Other authors have reported positive psychological benefits of writing. For example, family caregivers of people with dementia who were randomly assigned to a poetry-writing intervention experienced a sense of accomplishment in both writing a poem and caring for their family member [32]. They also reported a sense of catharsis, or emotional release, increased acceptance of their (caregiving) situation or for their care recipient, and greater self-awareness [32].

Participants valued MT4C as an accessible and reliable source of meaningful information and resources that could help them with their caregiving roles. They described the benefit of knowing more about dementia and the changes to expect in their loved one and their own roles and responsibilities. They also emphasized the value of links to information about topics such as legal issues and planning for placement. These findings are consistent with other research related to Web-based supports where caregivers expressed the importance of meaningful resources to support their roles [19].

The links to videos and quotes describing other caregivers’ experiences provided affirmation to many MT4C users and, thereby, reduced feelings of isolation and provided a sense of

connection with other caregivers. Other studies of Web-based interventions for caregivers confirm the importance of connections with other caregivers [20,22].

Participants also identified aspects of the Toolkit that were not beneficial. Not all caregivers liked to focus on themselves, to write out their personal thoughts, or to share their caregiving experiences in MT4C. Some caregivers chose to learn and share their experiences by other means, usually by attending a support group for caregivers, or speaking one-to-one with a counselor. Previous research related to Web-based supports indicates that caregivers value the opportunity to connect with professionals to support them in their caregiving [18,22].

Some caregivers felt that MT4C did not apply to their current situation or suit their needs, noting that it was either too early or too late in their caregiving journey to benefit from using MT4C. Some caregivers felt they had already dealt with an issue that was addressed by MT4C or had already obtained information from other sources, most often a local branch of the Alzheimer Society. In the pilot study of the Toolkit [25], participants suggested that it would be of most use to those in the early stages of caregiving; however, the findings of this study suggest that, in addition to the timing of the intervention, a caregiver's perceived need for support and information via a psychosocial Web-based intervention is important.

Participants were challenged with balancing multiple responsibilities and demands on their time, including, and in addition to, the care of an older adult with ADRD and MCC, yet they valued and learned from other caregivers' experiences (eg, videos and written comments) and suggested that future Web-based tools should include a means of connecting with other caregivers to share knowledge and experiences. These findings are congruent with recent qualitative evidence that demonstrates that Web-based social interventions benefit caregivers of persons with dementia by promoting sharing and companionship and reducing social isolation [13].

Implications

There are a number of implications for future practice and research related to Web-based interventions for caregivers of persons with ADRD and MCC arising from this study. Study results suggest that use of Web-based resources, such as MT4C, offer valuable support to help caregivers as they experience a range of complex caregiving roles and responsibilities. Findings indicate that future Web-based resources for caregivers should contain (1) opportunities for reflection on their caregiving journey and self-care; (2) options to share their caregiving experiences; (3) links to resources (eg, community health and support services, legal information) that they could use in planning for future caring; and (4) links to stories and videos of other caregiver experiences.

Participants appreciated that MT4C provided the opportunity to reflect on and write about their experiences as a caregiver and to learn from other caregivers through linked videos. Some

participants suggested that adding a feature to MT4C to enable caregivers to connect with one another (in real time or asynchronously) to share information, experiences, and caregiving strategies would be helpful. Incorporation of such features should be considered in the future development of Web-based supports for caregivers.

This Web-based intervention was developed with the theoretical lens of transitions theory [26] and thus, provides greater insight into the multiple, concurrent transitions experienced by caregivers who are caring for an older adult with ADRD and MCC. The application of transitions theory also facilitates the ongoing refinement of strategies to best meet caregivers' personalized needs. Future development of Web-based resources should consider a theory-based approach and how to best meet the complex transition-related needs of caregivers of individuals with both ADRD and MCC [33].

Many participants in this study had previously accessed or were currently using various community-based resources for caregivers of persons with ADRD. The resources listed in MT4C were focused on national or provincial services, and future development of Web-based resources could consider adding more locally available resources, perhaps with geospatial mapping.

Future research on Web-based supports such as MT4C could examine the perceptions of caregivers with a broader cultural and language diversity. Research is also needed to better understand the impact of Web-based supports for caregivers of persons with dementia and MCC when used in combination with other forms of support, including professional and peer support or telephone support.

Limitations

Currently, MT4C is only available in the English language and therefore, the sample showed little ethnic or cultural diversity. Follow-up beyond 3 months would have been useful to understand caregivers' use of the Web-based tool over a longer period of time.

Conclusions

Study results indicate that a self-administered psychosocial supportive Web-based resource helps caregivers of community-dwelling older adults with ADRD and MCC deal with their caregiving responsibilities. In particular, caregivers indicated that use of MT4C encouraged reflection, helped them to share their caregiving experiences, provided information and resources, and affirmed their caregiving roles. This, in turn, helped them to deal with caregiving roles and responsibilities, identifying supports for caring, caring for self, and planning for future caregiving roles and responsibilities. There is a need for further research in the field of Web-based supports for caregivers of older persons with ADRD and MCC as they have great potential as accessible and cost-effective ways to improve the well-being of these caregivers.

Acknowledgments

For their contributions, we offer sincere thanks to all of the study participants and our community partners: Alberta Caregivers Association; Alzheimer Society of Alberta and NWT; Alzheimer Society of Brant, Haldimand Norfolk, Hamilton and Halton; Alzheimer Society of Calgary; Alzheimer Society of Ontario; and Covenant Health Alberta. We also thank Dr Jennifer Swindle, Research Coordinator, and data collectors Ann Cotton, Annie Lam, Melissa Northwood, Lori Pollard, and Tracy Wildeman.

This study is part of a program of research (Aging, Community and Health Research Unit) supported by the Canadian Institutes of Health Research Signature Initiative in Community-Based Primary Healthcare (Funding Reference Number: TTF 128261) [34] and the Ontario Ministry of Health and Long-Term Care. MM-R was funded, in part, by the Canada Research Chairs programme, through her Chair in Person-Centred Interventions for Older Adults with Multimorbidity and their Caregivers, School of Nursing, McMaster University, Hamilton, ON, Canada.

Conflicts of Interest

None declared.

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Abbreviations

- ADRD:** Alzheimer disease and related dementias
MCC: multiple chronic conditions
MT4C: My Tools 4 Care or Transition Toolkit or Toolkit
RCT: randomized controlled trial
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Edited by G Eysenbach; submitted 14.07.17; peer-reviewed by D Gustafson, C Kerssens, L Dubenske; comments to author 21.09.17; revised version received 30.01.18; accepted 28.02.18; published 23.04.18.

Please cite as:

Ploeg J, McAiney C, Duggleby W, Chambers T, Lam A, Peacock S, Fisher K, Forbes DA, Ghosh S, Markle-Reid M, Triscott J, Williams A

A Web-Based Intervention to Help Caregivers of Older Adults With Dementia and Multiple Chronic Conditions: Qualitative Study
JMIR Aging 2018;1(1):e2

URL: <http://aging.jmir.org/2018/1/e2/>

doi: [10.2196/aging.8475](https://doi.org/10.2196/aging.8475)

PMID: [31518230](https://pubmed.ncbi.nlm.nih.gov/31518230/)

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Original Paper

Coproduction of a Theory-Based Digital Resource for Unpaid Carers (The Care Companion): Mixed-Methods Study

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Abstract

Background: Family and other unpaid carers are crucial to supporting the growing population of older people that are living outside residential care with frailty and comorbidities. The burden associated with caring affects carers' well-being, thus limiting the sustainability of such care. There is a need for accessible, flexible, and responsive interventions that promote carers' coping and resilience, and hence support maintenance of the health, well-being, and independence of the cared-for person.

Objective: This study aimed to coproduce a digital program for carers to promote resilience and coping through supporting effective use of information and other Web-based resources. Its overlapping stages comprised the following: understanding the ways in which Web-based interventions may address challenges faced by carers, identifying target behaviors for the intervention, identifying intervention components, and developing the intervention prototype.

Methods: The study was informed by person-based theories of coproduction and involved substantial patient and public involvement. It drew on the Behavior Change Wheel framework to support a systematic focus on behavioral issues relevant to caring. It comprised scoping literature reviews, interviews, and focus groups with carers and organizational stakeholders, and an agile, lean approach to information technology development. Qualitative data were analyzed using a thematic approach.

Results: Four behavioral challenges were identified: burden of care, lack of knowledge, self-efficacy, and lack of time. Local health and social care services for carers were only being accessed by a minority of carers. Carers appreciated the potential value of Web-based resources but described difficulty identifying reliable information at times of need. Key aspects of behavior change relevant to addressing these challenges were education (increasing knowledge and understanding), enablement (increasing means and reducing barriers for undertaking caring roles), and persuasion (changing beliefs and encouraging action toward active use of the intervention). In collaboration with carers, this was used to define requirements for the program. A resources library was created to link to websites, Web-based guidance, videos, and other material that addressed condition-specific and generic information. Each resource was classified according to a taxonomy itemizing over 30 different subcategories of need under the headings Care Needs (of the cared-for person), General Information and Advice, and Sustaining the Carer. In addition, features such as a journal and mood monitor were incorporated to address other enablement challenges. The need for proactive, personalized prompts emerged; the program regularly prompts the carer to revisit and update their profile, which, together with their previous use of the intervention, drives notifications about resources and actions that may be of value.

Conclusions: The person-based approach allowed an in-depth understanding of the biopsychosocial context of caring to inform the production of an engaging, relevant, applicable, and feasible Web-based intervention. User acceptance and feasibility testing is currently underway.

KEYWORDS

family caregivers; caregivers; self efficacy; information technology; frailty; Internet

Introduction

The Importance of Caring

In the United Kingdom, there are approximately 6.8 million informal carers (ie, unpaid individuals who provide a combination of physical, practical, and emotional care and support), with an estimated value to the economy of over £130 billion per year [1,2]. With the increasing population of older people living with multiple morbidities, frailty, and other complex health and social care needs [1,3], the importance of the contribution of carers to society will continue to grow. In the United Kingdom, this has been recognized in policy documents and legislation such as the Care Act 2014, which recognize the need for information, guidance, and support to assist caring roles [4].

Carers face numerous challenges, from having to respond to the often complex physical, psychological, and social care needs of the cared-for person, living with the uncertainty and isolation that is frequently associated with caring, to finding relevant information and support [5]. Informal caring may be particularly challenging for older people who may themselves be frail and often are in a spousal relationship with the cared-for person, and for middle-aged women with multiple roles [3]. Although the majority of carers are of working age with a peak age of 50-64 years [6], the number over the age of 65 years is increasing rapidly. The amount of time spent caring increases with age, with the highest levels of commitment in people aged 80-89 years [6].

A recent UK survey reported that 21% of carers said that they received little or no helpful information or advice and felt they did not know where to go for support with caring, with a further 45% stating they received some but not all the information they needed [7]. Lack of support for carers is recognized as a contributory factor to unplanned hospital admissions, prolonged hospital stays, and delays in discharging patients [8-10]. There is also evidence that intensive caring (ie, for more than 20 hours per week) has a detrimental effect on the carer's health [11]. Hence, there is a continuing and growing need for effective support for carers to undertake caring responsibilities [12], enhance their capacity to cope, and remain resilient [13].

Resilience is critical to sustainability as a carer and has been recognized as involving multidimensional individual factors, such as self-esteem, self-efficacy, skills and knowledge, family factors (such as supportive family relationships and resources), and societal elements (such as supportive social networks and access to resources), all of which may interact and change over time [14]. A recent realist review exploring strategies that enhance carers' resilience and coping [15] proposed a framework of interdependent domains (extending social assets, strengthening psychological resources, ensuring timely availability of key external resources, maintaining physical health, and safeguarding quality of life) and found that

interventions that most successfully enhanced resilience were those that utilized multi-domain components. For example, programs which combine tailored information with interaction among carers result in greater benefit to confidence, self-efficacy, stress, burden, and depression in contrast to those providing information alone [16,17].

Digital Technology

Digital technology may have considerable relevance to addressing issues faced by informal carers, but there have been relatively few targeted interventions. In the United Kingdom, there has been considerable interest and investment in the use of assistive technologies [18] to support older people. This includes telehealth apps that support the management of long-term health conditions and telecare apps that may involve personal and environmental sensors in the home. However, the overall take up of such intervention remains relatively low, and little research has explored adoption and use of such technologies from the perspectives of informal carers. One recent study found that informal carers play a crucial role in supporting the patient's decision to adopt and engage with such interventions, and concluded that efforts to increase adoption and engagement should adapt recruitment strategies and service pathways to support both the patient and their carer [19].

The internet and mobile apps are being increasingly used by carers to enable social interaction and provide access to information and advice that can support their caring role [16,20-22]. A benefit is ease of access from the convenience of the home without any need to leave the cared-for person [23-25], but barriers to uptake include lack of accessibility (eg, availability of a device that links to the internet), skills (eg, literacy and digital skills), motivation (eg, lack of awareness of the potential financial, social, and health benefits), and trust (eg, fear of crime, privacy, and knowledge of credible sources) [26,27]. Digital interventions that incorporate a personalized approach that is adaptive to ever-changing needs and issues are more likely to improve carers' health outcomes [28,29]. Encouraging user-generated content helps to address the difficulty of ensuring that carers make continued use of the intervention [30].

Older age tends to be associated with more limited engagement with digital technology, and in terms of age group, the lowest rate of internet use is in those aged over 65 years, with nonusers reporting a lack of interest as the main reason for not using the internet [31]. However, take-up is rapidly increasing among older people [32], and in the United Kingdom, there are various schemes to encourage older people to go online and to help them encourage their digital capability. For example, third-sector organizations such as Age UK are developing older people's understanding of the benefits of the internet and provide digital skills training and support through short courses for individuals or small groups, one-to-one tailored training, home visits, drop-in sessions, among others [33].

Although Web-based interventions and apps may significantly enhance carers' access to information and advice, identifying Web-based resources that are up to date, reliable, easy to use, and relevant can be time-consuming and challenging, especially for those who have limited information technology (IT) literacy [33]. Hence, the aim of the study described here was to address this by developing an easy-to-navigate Web-based program for carers that would provide users with personalized information and resources relevant to their context and needs, and thereby promote coping and resilience of the carer and improved health, well-being, and independence of the cared-for person. The scope of the project was limited to considering the needs associated with caring for adults with frailty and long-term conditions that are associated with ageing, and to developing a full working prototype of the intervention.

Methods

Underlying Theory

This intervention development study draws on a theory-driven process of coproduction [34,35], and it involved substantial patient and public involvement together with input from policy makers, commissioners, health and social care providers, and voluntary sector organizations. We established a carers' panel that included representatives of local carer support groups and Age UK, chaired by a carer and facilitated by the research team, and a stakeholder group with representatives of local health and social care commissioning and provider organizations, third-sector organizations, and voluntary organizations. Both groups contributed to all stages of the study. The study was also informed by the Behavior Change Wheel (BCW) framework [36,37], which was used to provide a systematic structured framework to focusing on behavioral issues relevant to caring that the intervention might address.

There were 4 key steps to the intervention development process: (1) understanding the ways in which Web-based interventions may address challenges faced by informal carers, (2) identifying and understanding target behaviors for the intervention, (3) identifying intervention components, and (4) developing the intervention prototype. Key aspects within each step are described below.

Step 1: Understanding the Ways in Which Web-Based Interventions May Address Challenges Faced by Informal Carers

Scoping Review

To understand the challenges faced by informal carers and how these might be addressed through Web-based interventions, information was initially gathered through a scoping literature review that focused on review papers and policy documents. In addition to identifying the challenges faced by informal carers, key topics for the review included developments influencing the use of Web-based technology, guidance on the development of Web-based interventions, and consumer surveys on the use of the internet and mobile devices. Web-based databases and journals (eg, PubMed, *Chronic Illness*) were explored in addition to Google Scholar searches (see [Multimedia Appendix 1](#) for search terms used).

Carer and Stakeholder Engagement

Carers and health and social care stakeholders were engaged in an iterative coproduction process over a 2-year period. This was conducted pragmatically to enable a broad range of individuals to contribute to the definition and refinement of ideas and themes.

Members of carer groups were invited to help us understand the experience of carers and their cared-for in relation to the challenges that are being faced and ways in which these might be addressed by a Web-based intervention. We used a topic guide that explored carers' experience of using Web-based information and resources, their views about how a Web-based intervention might be of benefit in their caring role, and we discussed potential intervention components iteratively to establish their relevance and acceptability. Detailed notes were kept, and key themes were identified and tested at subsequent group meetings as part of the coproduction.

Groups were identified through a snowballing process that initially involved publicly available listings of local voluntary organizations, and through key stakeholders who used their contacts to offer opportunities to attend carer support groups, dementia cafes, and to arrange focus groups. As a result, 5 local carer support groups and 6 companionship groups with both the carer and cared-for in attendance (attendees ranging from 1-15) were involved in the coproduction, and we also held 1 informal focus group with 12 attendees recruited from carer support groups for a more in-depth discussion about the emerging themes. In total, over 60 individuals participated, all of whom were current carers, or had recent experience of caring for an older family member or friend.

Alongside the work with carers, over 20 managers and health care professionals from local authority stakeholders and National Health Service (NHS) Clinical Commissioning Groups (CCGs) were involved in mapping the findings from the literature review and the insights acquired from the engagement with the carer and cared-for community onto local and national policy and strategic planning. Particular attention was given to challenges around the limited information and support carers receive at crucial points along the caring pathway, and the potentially detrimental effect this has on quality of life and well-being. Specifically, we identified ways in which this intervention development study fitted with local projects, developments, and resources, and how it might enable improved health and the avoidance of NHS activity, including unplanned hospital and care home admissions.

Existing Platforms and Support

A range of platforms were identified that might be relevant to addressing the needs of the carer and the cared-for using search engines and reviewing websites currently offering support to carers and older people requiring care, provided by voluntary organizations, local authority, and NHS sources. A search of the NHS Apps Library, Apple iTunes store, and Google was performed to identify any relevant apps. Additionally, the UK Clinical Trials Database was reviewed to identify any relevant current trials involving relevant interventions. Platforms and websites were reviewed to identify gaps in scope and content

and categorized into resources provided by charities or voluntary organizations, NHS or CCGs, local authorities, research projects, and private enterprises.

Step 2: Identifying and Understanding Target Behaviors

Drawing on the literature review, focus groups, and stakeholder engagement, we identified key behaviors that might be targeted by the intervention based on feasibility and potential impact. The analysis of the behavioral challenges facing carers was reviewed at carer meetings, with both groups considering how they affected the carer's resilience and their capability and capacity to cope. The BCW framework was used to help focus this process by identify aspects of the capabilities (C), opportunities (O), and motivation (M) that may enhance caring behaviors (B). This was done in conjunction with consideration of the Theoretical Domains Framework [36-38] and the domains known to be associated with carer resilience and coping [15]. These were refined as part of the carer engagement described earlier.

Step 3: Identifying Intervention Components

Specific intervention functions (eg, education, prompting, and training) from the behavior change techniques proposed by the BCW were then identified together with candidate intervention components (ie, intervention functions, behavior change techniques) [36,37,39]. These were refined through ongoing discussion with carers and stakeholder organizations, as described earlier, to develop shared understanding of the priorities for the intervention development. A workshop was then held with user and IT design involvement to develop a list of user "wants" related to these challenges that might be addressed by the intervention.

Step 4: Developing the Intervention Prototype

Operationalization of the selected intervention components into features emerged through a collaborative process involving an IT development company that utilized an agile, lean approach to programming, a panel of 5 carers who were recruited for their range of caring experience and then met monthly, and a study stakeholder group that met every 3 months. This process was informed by and facilitated by the research team. A user-story mapping approach was employed, whereby user stories informing intervention features were mapped out [40]. The emerging functionality was prioritized using the APEASE criteria (affordability, practicability, effectiveness and cost-effectiveness, acceptability, side-effects/safety, and equity) [36].

The panel of carers recruited from local support groups provided detailed input to the design of intervention features and content, reflecting their first-hand experience of carers' needs, whereas the stakeholder group (representatives from local health service commissioning organizations, public health, social care, health providers, third-sector and voluntary organizations) ensured that provider and policy perspectives were also incorporated. The lean approach was intended to eliminate wasteful programming, and through applying user stories and multiple interim releases, the carers' panel informed each stage of the prototype development.

Data Analysis

We undertook a narrative synthesis of the key issues and concerns that were described, and then undertook a thematic analysis [41] of the focus group discussion and stakeholder engagement, synthesizing this with the literature review findings. We analyzed the data iteratively so that emergent findings could be tested and refined through further steps in the coproduction process and used to inform the prototype design. Initial broad themes, such as "carer experience" and "sources of support," derived from the remit of the study were agreed by 2 members of the research team leading the analysis. Thereafter, the wider study team worked collaboratively to generate codes and to develop themes and subthemes through an iterative process. We validated the analysis through further discussion with the study's carers' panel.

Results

Although the study design describes sequential steps, in practice, it was an iterative process that continued over a 2-year period. Here we summarize key elements that emerged from each step and together informed the design and development of the intervention prototype.

The Potential for Web-Based Interventions to Address Challenges Faced by Informal Carers

The literature search produced 364 items, of which 74 were deemed to be relevant to the intervention development process. From synthesizing the key findings from the scoping review with the thematic analysis from the focus group discussions and stakeholder engagement, 4 behavioral challenges were identified: burden of care, lack of knowledge, self-efficacy, and lack of time.

Burden of Care

Carer burden describes the negative impact of caring on the carer's physical, psychological, emotional, social, and financial situation [42-44]. It contributes to carers often neglecting their own health needs [45]. Our qualitative data confirmed that carers often feel isolated and alone and felt that there was an expectation that they would find relevant support (including access to resources and supportive social networks) themselves. Carer support groups offered by local voluntary organizations, while valued for their peer support and companionship by those who used them, were often viewed as lacking availability, accessibility, and relevance.

Local health service and social care strategies recognized the need for personalized support to minimize the burden of care and to enhance coping and resilience [46]. This included offering assessments to carers to determine whether they are eligible for financial support or carers' breaks, as well as ensuring other services are in place, such as a telephone helpline, drop-ins, case workers, support groups, and training for carers provided by various third-sector organizations and smaller local voluntary organizations [46]. However, it was recognized that only a minority of carers accessed such services, and that barriers to access included limited hours of availability, location of services and activities, lack of transport, and difficulty in leaving the cared-for person [47].

Lack of Skills and Knowledge

Carers frequently describe having inadequate information regarding the health and social care needs of the care recipient and lack of knowledge of the support that is available and how to access it [48-51]. Focus group data confirmed that carers are often unsure about how to access support and useful information (from medical advice, financial and practical support to emotional support). Several participants stated that they tended to rely on informal advice and guidance from family and friends, or through talking to peers and sharing knowledge and experience.

Carers described a lack of support from health and social care professionals that was felt to continue across the entire caring pathway. This was identified as starting at the time of diagnosis, which was felt to be a crucial point where further support is needed, with insufficient consideration of likely care needs and how these might change over time. Although it was recognized that a great deal of information and advice is available, particularly Web-based, this was often perceived as being inaccessible or difficult to navigate, particularly under time constraints. Furthermore, the quality and reliability of information and advice was often unclear.

Three overarching categories of information and advice needs for carers were identified related to (1) the care needs of the cared-for person, (2) general information and advice, and (3) sustaining the carer. The literature review and focus groups were used to develop a taxonomy (Textbox 1) with over 30 items setting out key elements within each of these categories.

Lack of Time

Caring is time-consuming and can occupy the whole day and week. Many carers report that they are unable to take a break from their caring role [22]. Lacking time for themselves can exacerbate feelings of low mood, anger, and frustration [43,52,53]. It also contributes to social isolation, loss of relationships, and a narrowing of interests and activities. This was an important focus group theme, with many participants describing the difficulties of finding time both for themselves and for accessing resources and information that is useful to their caring role. The importance and value of taking time out and the need for respite was widely recognized, despite this being difficult to achieve.

Self-Efficacy

Self-efficacy is associated with mental and physical carer health, ability to cope with challenging situations, and the overall quality of caring provided [54-58]. Many focus group participants described having experienced a diminished sense of control over their lives when faced with the burden associated with caring and the challenges involved in determining and accessing support. In part, this was recognized as reflecting their own lack of knowledge and skills to identify and address diverse care needs. In addition, there were instances where

carers described difficulty effectively communicating with health and social care professionals, which could exacerbate low self-efficacy. Only a minority of carers feel confident in accessing community services to help them provide care, handle condition-specific behavioral problems, or manage the frustrations of caregiving [59].

Identifying and Understanding Potential Target Behaviors and Intervention Components

The key aspects of behavior change that emerged as relevant to the design of the intervention were education (increasing knowledge and understanding), enablement (increasing means and reducing barriers for undertaking caring roles), and persuasion (changing beliefs and encouraging action toward active use of the intervention). As shown in Textbox 2, many of the user “wants” that were identified at the workshop held with user and IT design input involved aspects of enablement and persuasion.

Refinement of Candidate Intervention Features

Keywords, values, and concepts encompassing the candidate intervention components were weighted according to the scale of IT programming involved in developing them. All the elements were seen as important, and most emerged as priorities for a full working product, reflecting the diverse and varied challenges associated with caring and the difficulty of prioritizing one need over another. The IT designers, therefore, decided on the order of developing the functional elements in relation to cost and resource availability.

The name of the intervention was regarded as crucial in terms of representing its ethos and in engaging the population it was intended to serve. A short list of names was created with carers, and this was then tested in a survey with local Age UK members; 35 responses were received, and the name Care Companion emerged as the clear preference. This was felt to reflect the concept of a personalized resource that would act as a reliable friend providing elements of support, advice, and guidance, both proactively and at times of more urgent need, along the pathway of caring.

Production of Intervention Prototype

Working with a Web design team, a minimum viable product that addressed the requirements identified in previous steps of the process was developed. Key requirements that emerged were that it should be intuitive to use, and hence accessible to people with limited IT literacy. It was designed to provide personalized access to information, resources, and advice according to the needs identified through the profile of the carer and the cared-for person. In addition to condition-specific resources aimed at increasing understanding about how to address varied and changing care needs, it would also contain more generic, locally relevant information and advice to help the carer navigate and gain access to the welfare and care system.

Textbox 1. Taxonomy developed for managing information needs.

1. Care needs

- Dealing with a diagnosis
- Signs and symptoms
- Therapies and treatments
- Personal care
 - Eating and Drinking
 - Toileting
 - Washing
 - Moving and Handling
 - Physical activity
 - Exercising the mind
- Practical aids and Adaptations
- Transport
- Housing
- Relocating to a care home
- Returning home from hospital
- End of life care
 - After death

2. General information and advice

- Confidentiality
- Communicating with health and social care
- Financial help and benefits
- Legal affairs
- Services and support
- Planning ahead
- Safeguarding
- Work
- Education and training

3. Sustaining the carer

- Emotional support
- Local support groups
- Respite
- Taking a break
- My physical health
- My mental health
- Relationships
- Living with loss and bereavement

Textbox 2. Carer “wants” identified for the intervention, with the key intervention functions shown in parentheses; asterisked elements were identified as higher priority.

- As a carer I want....
- trustworthy, locally relevant information, advice, and support to be available 24/7 (*Education, Enablement*)*
 - to be prompted to do useful things (*Education, Enablement, Persuasion*)
 - the statutory assessment to be at the forefront of my initial to-do-list so that I find out what entitlements, and so on, we are eligible for (*Education, Persuasion*)*
 - to be carefully prompted to “Look to the Future” (eg, lasting power of attorney) so that I feel better prepared (*Enablement, Persuasion*)*
 - key information tips and things to look for (eg, warning signs) based on the profile of the person that I care for (*Education, Enablement*)*
 - tips and advice relevant to my situation so that I am better able to tailor my care (*Education, Enablement*)*
 - a prepopulated list of relevant contacts that I can add to so I can quickly get hold of people when necessary (*Enablement*)*
 - to have a “saved” section for information I find useful so that I can easily use it again (*Enablement*)*
 - to browse Web-based content by condition/location/type/tags and highly rated so I can find relevant information easily (*Enablement*)*
 - to bookmark resources so I can access them later (*Enablement*)*
 - to learn from other carers’ experiences about how they have coped with similar challenges to those that I am facing (*Education, Enablement*)
 - to be asked about my well-being so that the system can monitor my well-being (*Persuasion*)*
 - to be asked about the well-being of the person that I care for so that the system can monitor their well-being and proactively provide me with advice or guidance (*Education, Enablement*)*
 - to be prompted to read information or seek help if my mood changes or is persistently negative so that I am cared for too (*Persuasion*)*
 - to see automatically generated notifications about new resources and information relevant to me so that I’m kept abreast of additions to the site
 - to be able to record key events or incidents in my journal with a date and time (*Enablement*)*
 - to be able to view previous entries chronologically so that I can see trends (*Enablement*)
 - to print entries from my journal between specific dates in a clear and legible manner so I can use them to help me communicate with health and social care professionals (*Enablement*)
 - to have an area on the site aimed at giving me a break so that I am able to have moments for myself (*Persuasion*)*
 - a frequently asked questions (FAQs) section so I can better understand how to make the most of the site (*Education, Enablement*)*
 - a glossary so that I can understand the language used in the context of caring (*Education*)

Textbox 3. Criteria used for assessing the quality of materials being considered for inclusion in the resources library. Quality assessed with the following scale: 1 (very poor); 2 (poor); 3 (acceptable); 4 (good); and 5 (very good).

- Presentation: Is information presented in a clear and concise format? Is the source of information free from adverts and pop-ups?
- Coverage: How well does the information cover the topic of the resource? Is it clear who the information is aimed at?
- Accuracy: Is the information consistent with that you believe to be true? Is the information verified by other sources?
- Currency: Is the information up to date? When was it initially uploaded and has it been recently reviewed?
- Accessibility: Is the information freely accessible? Is the source of information easy to access and navigate through?
- Readability: How easy is it to understand what is written? Is the information communicated effectively? Does the source avoid excessive jargon and technical terms?
- Objectivity: How objective is the source? Does the information attempt to coerce or influence the reader?
- Authority: Is the source of the information a genuine authority on the subject? Is the information mostly fact rather than opinion?

Alongside the IT development work, a group of medical students, all of whom had personal experiences related to caring, collaborated with the carers’ panel on establishing a systematic approach to identifying webpages and resources to be linked to the intervention’s resources library. This included drafting brief descriptors of each resource (1 or 2 sentence lay language summaries). The resources were tagged according to the conditions that they related to and the taxonomy described in

Textbox 1. A quality assurance process was developed drawing on established systems [60-62] which, together with peer review, ensured that there was a transparent auditable trail to account for the content included in the intervention’s library (see **Textbox 3**). Only resources that scored at ≥ 4 on all measures were considered for inclusion, and where several alternative resources were available, the highest scoring items were selected. The carers’ panel emphasized this as being important,

given the difficulty of knowing the trustworthiness of resources identified by standard search engines. Initially, we focused on incorporating resources relevant to caring for a person with dementia, given the prevalence, importance, and complexity of this condition, and then broadened the content to cover other long-term conditions associated with frailty.

In this way, the resource library was designed to provide signposting to information, guidance, video, and other resources according to transparent quality standards, with an underlying system of classification that would support powerful search, view, and retrieval capabilities. Sections aimed at improving well-being and coping, such as “take a break” tips, ideas, and resources, were specifically aimed at reducing the burden of caring and maintaining carer resilience.

In addition to the resources library, the intervention includes a journal in which the carer can record day-to-day key information about the cared-for person (eg, regarding contacts with health care professionals, changes in condition) and a mood monitor. Changes that occur over time in self-ratings recorded in the mood monitor may drive messages to the user, such as encouragement to seek professional advice. There is also a “useful contacts” directory that can help the carer access support when needed, such as from local authority and third-sector organizations.

A further aspect is that the Care Companion should be dynamic and learn from how the carer uses the intervention and the ways in which this may reflect the changing needs of the cared-for person and the carer. At regular intervals, the user is prompted to revisit their profile to provide further information that can be used to drive the provision of relevant, personalized notifications. In this way, the intervention aims to prompt and motivate users to access information that is likely to be relevant to their needs but which they might not have considered as being relevant. The importance of addressing “not knowing what you don’t know about” was something that had been emphasized by many carers throughout the development process.

Discussion

Principal Findings

Family and other unpaid carers are enormously important to society and yet often feel unsupported and lacking in key knowledge, information, and skills that might make the caring role more sustainable. Current services in the United Kingdom lack accessibility and availability, and Web-based resources and apps are often difficult to discover and may lack relevance. Here, we have described the coproduction of an intervention aimed at helping informal carers maintain their resilience and cope more effectively through gaining access to personalized information, services, and resources. The intervention was developed systematically based on a theory-based behavior change model, existing research, and involvement of multiple stakeholders and carers. Its design reflects the importance of a multicomponent intervention that carers can use flexibly over time according to the changing needs and requirements. Through completing the profile, the intervention can filter relevant information in terms of its applicability to the conditions and

context of the cared-for person, and through notifications, the intervention can suggest important or useful actions to be undertaken. In addition, user engagement is encouraged through allowing carers to save resources to a favorites section, adding entries to the journal and making use of a mood monitor. Hitherto, few digital interventions targeting the carer community have used a theoretical basis for intervention development or provided information on how the intervention was developed [16,63-65].

The “person-based” approach that we applied [35] focused on understanding and accommodating the perspectives of carers through synthesizing evidence from the research and policy literature with focus groups and input from carers at every stage of the developmental process. This ensured that the IT designers drew on an in-depth understanding of the biopsychosocial context of carers, and through working to an agile lean methodology could iteratively modify its design to make it more engaging, relevant, applicable, and feasible. In addition, the person-based approach enabled us to identify and highlight the distinctive ways that the intervention has been designed to address key context-specific behavioral issues.

Strengths and Limitations

A key strength of this study is its participatory approach which included iterative involvement from individual carers, representatives of carer groups, local authority managers, health service commissioners and clinicians, voluntary sector and third-sector organizations, mental health services, clinical and behavioral psychologists, and IT design and software engineers.

Coproduction involving an ongoing collaboration with carers enabled the emergence of in-depth understanding of how carers might use the Care Companion, which in turn influenced each stage of the intervention development. It was informed by theories relating to resilience and coping and the BCW. Together, this allowed a systematic framework in which specific behavioral components to promote resilience and coping could be defined and prioritized. The BCW proved valuable in understanding the capabilities, opportunities, and motivation to maintain coping and resilience as a carer, and helped in the selection of intervention functions and specifying features. It facilitated an extensive range of intervention options to be considered and the eventual definition of an in-depth specification of requirements that were grounded in evidence and the experience of carers.

This required considerable commitment from carers, reinforced by clear demonstration that their views and insights were being directly reflected in the intervention development. The value of this input was recognized with participants being paid an honorarium in line with nationally recommended guidance [66]. In addition, the wide representation of stakeholder organizations that were involved in the development has been a strength that ensured buy-in and support for the future use and dissemination of the intervention.

The use of the BCW framework facilitated the inclusion of contextual and environmental influences into the design of the intervention [35,67]. Limitations were that the BCW was unable to provide guidance on the operationalization of potential

intervention components into program features. Hence, it provided a useful starting point and a structure for considering functionality, but much of the design was reliant on the expertise and creativity of the carer and stakeholder groups, including the prudent advice on feasibility and cost from the IT designers, on how to best translate the proposed components into prototype functionality. The challenges faced by informal carers are vast and complex. Specifying a single behavior in terms of who, what, where, and when, as advised by the BCW model, was not appropriate, and rather than the sequential steps in the development, there was a need for a more iterative and overlapping process. However, it enabled us to consider potential intervention features in terms of their relevance, acceptability, and feasibility. There are few evidenced examples of applying the BCW approach to complex behaviors through digital media, and its effectiveness in this context requires further study [68].

Future Work

The next stage in the intervention development is a feasibility study to test the usability and acceptability of the Care Companion prototype with a wider group of users. This includes the feasibility of peer to peer dissemination of the Care Companion to identify the extent to which peers might be included in the design of a future implementation and adoption strategy. We will be exploring carers' experience of using the

Care Companion, barriers to uptake, and concerns (such as information security) that may limit usage. This work is underway and will be reported in a subsequent publication.

We are also working with commissioners of local services for older people and their carers to define how the wealth of data that could be collected longitudinally by the Care Companion can be used to inform commissioning decisions. Commissioners will have the opportunity to suggest data gathering questions that are locality-specific (ie, only seen by users that are living within these areas) and relevant to commissioning of services, and to define requirements for reporting on the take-up and use of the Care Companion by locality.

Conclusions

This paper has described how a theory-based approach to intervention development provided a systematic and comprehensive framework for designing a program that addresses a highly complex set of behaviors relevant to caring. The strength of the coproduction described here is its inclusiveness, which ensured that a range of perspectives were iteratively engaged in informing and refining its content and features. As such, it includes many features which might otherwise have not been prioritized for inclusion. The effectiveness of the intervention on carers' resilience and coping, and the subsequent effect on the cared-for person's health and well-being, will be studied in future research.

Acknowledgments

The authors are grateful to all the stakeholders who have contributed to and informed the development of the Care Companion. This includes managers, and health and social care specialists, from Coventry and Rugby CCG, South Warwickshire CCG, Coventry City Council, Warwickshire County Council, South Warwickshire NHS Foundation Trust, Age UK Warwickshire, and numerous carers groups, together with Global Initiative Ltd. The authors are particularly grateful to the members of the Carers' Panel, chaired by Gillian Grason Smith for their enthusiasm, ideas, and commitment, and also to the team of medical students led by Sam Covins for their input into the development of the content and resources within the Care Companion. In addition, the authors thank the following research assistants for their involvement in various stages of the development: Julia Everitt, Dr Hashim Syed, Roxanne Nanton, and Emma Fairclough. The authors are grateful to the following for funding this study: NHS Coventry and Rugby CCG, NHS South Warwickshire CCG, University of Warwick, and the Quality of Life Trust, together with Global Initiative Ltd's social responsibility fund.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Keywords used in literature search.

[PDF File (Adobe PDF File), 14KB - [aging_v1i1e1_app1.pdf](#)]

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Abbreviations

BCW: Behavior Change Wheel
CCG: Clinical Commissioning Group
IT: information technology
NHS: National Health Service

Edited by G Eysenbach; submitted 23.09.17; peer-reviewed by L Boots, A Poli; comments to author 03.12.17; revised version received 29.01.18; accepted 31.01.18; published 28.02.18.

Please cite as:

Dale J, Loew J, Nanton V, Grason Smith G

Coproduction of a Theory-Based Digital Resource for Unpaid Carers (The Care Companion): Mixed-Methods Study

JMIR Aging 2018;1(1):e1

URL: <http://aging.jmir.org/2018/1/e1/>

doi: [10.2196/aging.9025](https://doi.org/10.2196/aging.9025)

PMID: [31518238](https://pubmed.ncbi.nlm.nih.gov/31518238/)

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Original Paper

A Tool That Assesses the Evidence, Transparency, and Usability of Online Health Information: Development and Reliability Assessment

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Abstract

Background: The internet is commonly used by older adults to obtain health information and this trend has markedly increased in the past decade. However, studies illustrate that much of the available online health information is not informed by good quality evidence, developed in a transparent way, or easy to use. Furthermore, studies highlight that the general public lacks the skills necessary to distinguish between online products that are credible and trustworthy and those that are not. A number of tools have been developed to assess the evidence, transparency, and usability of online health information; however, many have not been assessed for reliability or ease of use.

Objective: The first objective of this study was to determine if a tool assessing the evidence, transparency, and usability of online health information exists that is easy and quick to use and has good reliability. No such tool was identified, so the second objective was to develop such a tool and assess it for reliability when used to assess online health information on topics of relevant to optimal aging.

Methods: An electronic database search was conducted between 2002 and 2012 to identify published papers describing tools that assessed the evidence, transparency, and usability of online health information. Papers were retained if the tool described was assessed for reliability, assessed the quality of evidence used to create online health information, and was quick and easy to use. When no one tool met expectations, a new instrument was developed and tested for reliability. Reliability between two raters was assessed using the intraclass correlation coefficient (ICC) for each item at two time points. SPSS Statistics 22 software was used for statistical analyses and a one-way random effects model was used to report the results. The overall ICC was assessed for the instrument as a whole in July 2015. The threshold for retaining items was ICC>0.60 (ie, “good” reliability).

Results: All tools identified that evaluated online health information were either too complex, took a long time to complete, had poor reliability, or had not undergone reliability assessment. A new instrument was developed and assessed for reliability in April 2014. Three items had an ICC<0.60 (ie, “good” reliability). One of these items was removed (“minimal scrolling”) and two were retained but reworded for clarity. Four new items were added that assessed the level of research evidence that informed the online health information and the tool was retested in July 2015. The total ICC score showed excellent agreement with both single measures (ICC=0.988; CI 0.982–0.992) and average measures (ICC=0.994; CI 0.991–0.996).

Conclusions: The results of this study suggest that this new tool is reliable for assessing the evidence, transparency, and usability of online health information that is relevant to optimal aging.

(*JMIR Aging 2018;1(1):e3*) doi:[10.2196/aging.9216](https://doi.org/10.2196/aging.9216)

KEYWORDS

knowledge translation; Consumer Health Information; consumer health standards; internet standards; Patient Education as Topic; Patient Education as standards; critical appraisal; online health information; reliability analysis

Introduction

Many people increasingly turn to the internet as a source of information, motivation, and support for healthy living and management of common health conditions [1,2], including many older adults (those 60 years or older) [3]. At least half of the older adults who use the internet search for online medical or health-related information [4], and many of those who do not use the internet themselves have friends, family, and informal caregivers who seek online information on their behalf [2,5]. The availability of online health information has been shown to aid self-management of health conditions, particularly if the information can be tailored to the patient's needs and/or paired with support [6-8].

Furthermore, access to online health information can help people stay up to date with emerging information about their health conditions and can facilitate shared decision-making between patients and health care providers [9,10]. However, for online health information to be helpful for patients it needs to be evidence-based. For online health information to be evidence-based, it should be based upon evidence that has been systematically and scientifically obtained [11]. Studies show, however, that much of the online health information accessed by the general public has not been informed by good quality evidence [12-18] and is therefore unlikely to produce the purported health benefits. Finally, studies show that the general public lacks the skills necessary to distinguish evidence-based resources from those that are not [19-22].

As Khazaal et al [23] noted, "content quality indicators are warranted in order to help patients and consumers judge the quality of online information and to discriminate good sites from others." As a result, a number of tools have been developed to assess the extent to which evidence has been used in developing online health information. Some of these tools have even undergone psychometric testing. In 1999, Kim et al [24] identified 29 published rating tools and extracted 165 explicit criteria which they grouped into 13 distinct categories. The categories ranged from content (30% of criteria) to authority (11% of criteria) to user support (2% of criteria) [24]. In 2002 a review by Eysenbach et al [19] identified 86 unique quality criteria among 79 studies evaluating the quality of websites. The authors reduced these to the 22 most commonly-used criteria and concluded that operational definitions of the criteria were needed. In 2005 Bernstam et al [25] published a paper of operational definitions for these 22 criteria and reported that interrater reliability for 18 of the 22 items was good when precise operational definitions were provided. However, Bernstam et al [25] also noted that for some criteria, even when

precise operational definitions existed, they could not be reliably assessed.

In yet another review by Gagliardi and Jadad published in 2002 [26], 98 "award-like" instruments used to rate the quality of online health information were identified. "Award-like" instruments take the form of logos or "seals of approval." Only 11 of the 98 instruments provided information by which they could be evaluated, and none had been validated [26]. The 11 instruments were assessed against three criteria judged to be indicators of accurate online information (authorship, attribution, and disclosure), of which only three contained all three indicators of accuracy, and none which had been tested for reliability [26].

In 2005 Bernstam et al [27] published another review of tools to assess the quality of health information that could be used by patients. To be included in the review the tool had to be: (1) available to consumers, (2) made up of a limited number of items (10 or fewer), (3) made up of items that were objective and therefore assessable by consumers, and (4) readable. A total of 273 unique tools were identified; however, only 21 had 10 or fewer items, of which only 7 were made up of entirely objective items, with only one readable at a grade 8 reading level (which is no longer available).

In 2006 Provost et al [28] conducted a review of the literature to identify constructs thought to indicate quality of online health information, with the aim of developing a new instrument to assess the quality of health-related websites. The authors employed the 13 categories identified by Kim et al [24] and categorized 384 items identified through their literature review to these 13 categories. The authors eliminated criteria through discussion regarding 3 aspects of feasibility: (1) *externality*, being feasible to answer the question with the information available on the website; (2) *expertise independent*, being feasible to answer by the intended user of the scale independently of their credentials; and (3) *timeliness*, time efficiency in assessing the item. The study convened a panel of six experts to assess the items for relevance, importance, clarity, and feasibility [24]. The result was a new tool called the WebMedQual scale comprised of 8 categories, 8 subcategories, 95 items, and 3 supplemental items [24]. However, the tool was not tested for reliability.

Finally, Breckons et al [29] published a review in 2008 comparing 12 instruments that were used to assess the quality of complementary medicine information on the internet. The instruments contained between 4 and 43 items and varied considerably on what they assessed and how easy they were to use. While there was good agreement across the 12 instruments

in the rank order of the assessed websites, only two of the instruments had been tested for reliability.

Clearly, a considerable amount of effort has been invested in the development of tools to assess the quality of online health information. However, it is not yet clear if there is one tool that is superior to all others with respect to being quick and easy to use and that reliably determines the quality of online health information. Furthermore, while quality assessment tools may help older adults more easily identify evidence-based information, a potentially more effective service might be one that compiles available online health information in one place, and assesses its quality. In particular, gateways or portals have been deemed particularly useful as they provide access to content that has been prescreened and deemed of high enough quality to be approved by a governing organization [29].

The McMaster Optimal Aging Portal (the Portal), launched in 2014, is a health information website that serves as such a gateway, providing access to online resources about healthy aging that have been preappraised for quality [30-32]. Healthy aging is, "a lifelong process of optimizing opportunities for improving and preserving health and physical, social, and mental wellness, independence, quality of life, and enhancing successful life-course transitions" [33]. The Portal offers direct and easy access to evidence-based information about how to stay healthy, active, and engaged, and how to manage health conditions as one grows older. Web Resource Ratings are one type of knowledge product available on the Portal. For the purposes of the Portal, a Web resource (online health information) is any item found online that can be read, watched, listened to, or interacted with (eg, fact sheets, webpages, and videos). The aim of the Web Resource Rating function is to assess the quality of online health information, to convert these assessments into star-ratings, and to post the star-ratings for individual online health information products on the Portal. The overarching goal is to help older adults easily identify and link to the highest quality online health information. The ability to complete this function on the Portal is dependent on the existence of a reliable quality assessment tool that is both easy and quick to use. The purpose of this study was to determine if there was at least one tool in existence with proven reliability that was quick and easy to use. If no such tool was identified, efforts would then be directed toward developing a new tool that would be quick and easy to use, followed by testing the new tool for reliability.

Methods

Identification of Articles Describing Instruments

A search for instruments that assessed the quality of online health information was conducted through an electronic search of Medline from 2002 and 2012, a focused internet search, and through suggestions made by key informants. The search strategy used is described in [Multimedia Appendix 1](#). Title and abstract screening occurred with articles meeting the following inclusion criteria being retained for further assessment: an evaluation of an instrument assessing the quality of online information was reported, or it was a literature review of instruments assessing the quality of online information. Articles were excluded if: the focus was a health condition-specific

website or tool, the instrument was only assessed for readability, or the instrument was physician-centered.

Assessment of Relevance of Unique Instruments

Relevant articles underwent a second relevance assessment to identify instruments within those articles that: (1) had been assessed for reliability, (2) assessed the quality of the evidence used to create online information, (3) had fewer than 15 criteria, and (4) were suitable for use by citizen raters.

Relevance Assessors

Assessments were independently completed by two raters. All raters had achieved (or were in the final year of) an undergraduate degree at McMaster University, had been working with the Portal for 5-10 hours per week for 1-6 months, and received training from the project coordinator (SW).

Identification of Time to Complete Each Instrument and its Ease of use

Instruments retained from the second relevance assessment were then used to assess a sample of online health resources. Raters took note of how long it took to complete assessments for each instrument as well as how complex items within each instrument were to apply. Agreement between raters was assessed and the Portal team met to decide which instruments, if any, were appropriate for the purposes of the Portal. Assessments were completed by dyads with one assessor being a staff member (as described above for relevance assessment), and the second being a Lead of the Portal (MD, BH, JL; each of whom have decades of experience in evidence-based practice and appraisal of evidence) [31].

Development of a new Instrument

No one tool was deemed sufficient for its intended use for the Portal, so the development of a new instrument was begun. Items for the new instrument were crafted either anew by the Portal team or selected from the previously identified instruments. Items were developed and/or selected to meet the following expectations: (1) the answer needed to be dichotomous (Yes or No); (2) the items were suitable for assessing a Web resource on a website, rather than a website; (3) the information needed to assess the item would reasonably be included on the webpage of the resource; (4) had good reliability; and (5) was suitable for use by citizen raters. The items were organized into the following three categories: (1) the quality of the evidence which informed the Web resource, (2) the transparency of the resource development process, and (3) the usability of the resource. A guidance document explaining each item and how it should be rated was created and used to train raters, and was used as a resource while raters completed their assessments.

Reliability Assessment

A set of 10 items was formally assessed for reliability in April 2014 using 120 Web resources relevant to healthy aging (2 raters, therefore a total of 240 ratings), with a second reliability assessment being conducted in July 2015 using a different set of 107 Web resources (214 ratings). The Portal used in this study employs a two-stage process for identifying and selecting Web resources. These tasks were completed by the same staff as described above for relevance assessment. In stage 1 internet

searches are conducted to identify websites (worldwide) providing information relevant to healthy aging (ie, physical activity, nutrition, social engagement). Websites are assessed for the following criteria: the website is not funded by a company trying to sell products or services, content of the site is relevant to healthy aging, the website includes content intended for use by citizens, and the website is freely accessible. Websites meeting all of these criteria are deemed relevant, and move on to stage 2, which is identification and selection of Web resources housed on the website. Potentially relevant resources are uploaded to a content management system. Each Web resource is then assessed for the following: the resource is not funded by a company trying to sell products or services, the resource is relevant to healthy aging, the resource is intended for use by citizens, and the resource is less than 3 years old. Web resources meeting all four criteria then undergo quality assessment.

For this study a team of eight raters completed the quality assessments, with each Web resource being rated by two independent raters. Consistent with relevance assessment, all raters had achieved (or were in the final year of) an undergraduate degree at McMaster University and had been rating resources for 1-6 months part-time (5-10 hours per week). All raters received training on using the instrument. Ratings were conducted independently and conflicts were resolved through discussion. A third reviewer (MD or SW) resolved any conflicts in ratings. Data were exported in bulk from the online rating system into SPSS Statistics 22 software for statistical analyses.

Reliability between two raters for each item included in the instrument was assessed using the intraclass correlation coefficient (ICC). The ICC is defined as the correlation between one measurement on a target (in this case, the Web resource) and another rating on the same target [34]. Four value ranges, as outlined in McDowell [35], were used to interpret the ICCs: ICC values >0.75 were considered “excellent” reliability; values from 0.6 to 0.74 had “good” reliability; values from 0.4 to 0.59 had “fair” reliability; and values below 0.4 had “poor” reliability. The threshold for retaining items was >0.60 (“good” reliability).

ICC values were assessed for each individual item in both 2014 and July 2015. The overall ICC was assessed for the instrument as a whole in July 2015 once the final set of items was identified. A one-way random effects model was used to report the results; this model assumes that raters are randomly selected from a population of raters and different pairs of raters rate each product. Both the average and single measures were included in the analysis. Average measures calculate the mean reliability (selection of the same rating for the same criteria) of multiple raters. Single measures calculate the reliability of a single rater, accounting for any potential rater effect (ie, chance and error affecting variance in rater selections) [34].

Results

Findings From the Literature Search for Existing Instruments

Once duplicates were removed, 585 articles were identified, of which 19 were either an evaluation of an instrument assessing the quality of online information or a literature review of instruments assessing the quality of online information [23-29,36-47]. Among the 19 articles there were no instruments identified that met all of the following criteria: (1) had been assessed for reliability, (2) assessed the quality of the evidence used to create a Web resource, (3) had fewer than 15 criteria, and (4) were suitable for use by citizen raters. However, five instruments met two of the criteria: had been assessed for reliability and contained criteria that assessed the quality of the evidence used to create a Web resource. These five instruments were retained for further assessment. These instruments included the DISCERN instrument [48], the Information Quality Tool (IQT) [42], the Quality Scale (QS) [49], the Minervation validation instrument for healthcare websites (LIDA tool) [50], and a set of 22 criteria identified by Bernstam et al [25] as those most commonly used to assess the quality of online health information.

The DISCERN instrument is a 16-item instrument using a 5-point Likert scale rating system, which was developed by an expert panel to evaluate the reliability and quality of treatment information for a particular health problem [48]. The IQT is a 21-item instrument of yes or no questions about a resource’s authorship, sponsorship, currency, accuracy, confidentiality, and navigability. Criteria are weighted by importance and a total score is calculated that ranges from 0 to 4 [42]. The QS is a 7-item instrument using a 3-point Likert scale rating system. The total score can range from 0 to 14 and includes criteria related to ownership, authorship, source, currency, interactivity, navigability, and balance [49]. The LIDA Instrument developed by Minervation looks at three areas to evaluate online health information (accessibility, usability, and reliability) using a four-point scale ranging from *always* to *never*. There are 12 sub-subsets of questions and total scores are generated for each of the three sections [50]. In Bernstam et al [25], authors evaluated the interrater agreement of 22 common technical quality criteria. Criteria included questions related to specific webpages (eg, authorship, credentials, date, and references) as well as questions related to the general website (eg, internal search engine, feedback mechanism, and editorial review process). Use of the five instruments to assess a sample of Web resources by Portal dyads determined that they all took too long to complete, or were too complex to apply, and therefore a new instrument was developed with reliability being formally assessed in April 2014 on a set of 10 items.

Table 1. Reliability assessment of Web Resource Rating criteria measured by intraclass correlation coefficient, April 2014. n=120 resources/240 ratings.

Criteria	Intraclass Correlation Coefficient (95% CI)	
	Single measures	Average measures
Evidence Base		
1. Does the product comment on the quality of the evidence?	0.929 (0.900-0.950)	0.963 (0.948-0.975)
2. Does the product use language that communicates the strength of recommendation(s)?	0.548 (0.410-0.662)	0.708 (0.581-0.796)
Transparency		
3. Are sources provided for each claim/recommendation?	0.728 (0.632-0.802)	0.843 (0.774-0.890)
4. Authorship disclosure. Is the authors' or editors' name and affiliation disclosed?	0.465 (0.313-0.594)	0.635 (0.476-0.745)
5. Is advertising clearly labelled?	0.838 (0.776-0.884)	0.912 (0.874-0.939)
6. Is the date of creation within the last three years?	0.822 (0.754-0.872)	0.902 (0.860-0.932)
7. Is there a feedback mechanism?	0.724 (0.627-0.799)	0.840 (0.771-0.888)
Usability		
8. Minimal scrolling	0.489 (0.340-0.614)	0.657 (0.508-0.761)
9. Logical flow	0.660 (0.547-0.750)	0.796 (0.707-0.857)
10. Accessibility (For text content: <i>can text be resized or is there a screen reader?</i> For nontext content: <i>is a transcription available?</i>)	0.719 (0.620-0.795)	0.836 (0.765-0.886)

Results of the Reliability of the new Instrument

The results are presented in [Table 1](#). Using the data for single measures, seven items had ICCs >0.60: (1) *Does the product comment on the quality of the evidence?*; (2) *Are sources provided for each claim/recommendation?*; (3) *Is advertising clearly labeled?*; (4) *Is the date of creation within the last three years?*; (5) *Is there a feedback mechanism?*; (6) *Is there logical flow?*; and (7) *Is the text accessible?*

Of the three items with ICCs <0.60, one was removed from the instrument (*minimal scrolling*), and the other two (*language that communicates the strength of the recommendation and authorship*) were kept, as they were regarded as priority items and had been identified in other instruments as important criteria [25,42,49]. Modifications were made to the wording of these two items for clarity, as well as the seven with ICC values >0.60, and they were reassessed in July 2015. In addition, four new items were added at that time that assessed the level of research evidence the Web resource was informed by: (1) *Is the Web resource informed by published single studies?*; (2) *Is the Web resource informed by randomized controlled trials?*; (3) *Is the Web resource informed by systematic reviews/meta-analyses?*;

and (4) *Is the Web resource informed by best practice guidelines?* Of this set of 13 items, six were related to the quality of the evidence, five were related to the transparency of the development of the Web resource, and two assessed usability.

The results of this reliability assessment illustrated that 11 of the 13 items had excellent ICC scores, and two (*Is the strength of the recommendations provided?* and *Are peer-reviewed sources provided for each claim or recommendation?*) had good ICCs ([Table 2](#)). Furthermore, six items had an ICC of 1. Given the results of this assessment, it was decided that no further testing of the tool was required, and these 13 items became the final set of items for the instrument.

The ICC of the total rating score for the 13 items, calculated with a one-way random model, has excellent reliability with both single measures (ICC=0.988; CI 0.982-0.992) and average measures (ICC=0.994; CI 0.991-0.996), as depicted in [Table 2](#). These results indicate that the instrument is highly reliable, whether ratings are conducted by a single, independent rater or are averaged from the results of at least two raters, with only approximately 1% of the variance in Web resource ratings attributed to chance or other factors. The final version of the tool is included in [Multimedia Appendix 2](#).

Table 2. Reliability assessment of Web Resource Rating criteria measured by intraclass correlation coefficient, July 2015. n=107 resources/214 ratings.

Criteria	Intraclass Correlation Coefficient (95% CI)	
	Single measures	Average measures
Evidence Base		
1. Is the Web resource informed by published single studies?	0.933 (0.904-0.954)	0.965 (0.949-0.976)
2. Is the Web resource informed by published randomized controlled trials?	1	1
3. Is the Web resource informed by published systematic reviews/meta-analyses?	1	1
4. Is the Web resource informed by best practice guidelines?	1	1
5. Is the quality of the evidence reported?	0.945 (0.921-0.962)	0.972 (0.959-0.981)
6. Is the strength of recommendations provided?	0.660 (0.538-0.755)	0.795 (0.700-0.860)
Transparency		
7. Are peer-reviewed sources provided for each claim/recommendation?	0.740 (0.641-0.815)	0.851 (0.781-0.898)
8. Is the author's or editor's name and affiliations disclosed?	0.942 (0.917-0.960)	0.970 (0.957-0.980)
9. Is the advertising clearly labelled (or is there no advertising)?	1	1
10. Has the Web resource been created or updated within the last 3 years?	0.926 (0.893-0.949)	0.961 (0.943-0.974)
11. Is there a feedback mechanism?	1	1
Usability		
12. Logical flow: is the information easy to follow?	1	1
13. Accessibility: does the Web resource offer options to access the information? <i>Can text be resized or is there a screen reader? For nontext content, is a transcription or subtitle option available?</i>	0.944 (0.920-0.962)	0.971 (0.958-0.980)
Total Score	0.988 (0.982-0.992)	0.994 (0.991-0.996)

Discussion

Assessment Criteria for Online Health Information

The purpose of this study was to determine if at least one instrument with proven reliability existed that was quick and easy to use for the assessment of online health information. If no such instrument was identified, the focus then became the development of a new instrument that was quick and easy to use, and to test the instrument for reliability. Although various quality assessment instruments specific to online resources exist, it was determined through this study that all identified instruments either had poor reliability or had not been assessed for reliability, had too many criteria to make the tool easy to use, or were not suitable for use by citizen raters.

As a result, a new instrument was created that incorporated items from existing instruments, as well as the development of new criteria. Formal reliability assessment, undertaken between April 2014 and July 2015, resulted in the identification of the 13 items included in the final version of the new instrument. The ICC assessment showed that—as of July 2015—the final set of 13 items had good-to-excellent reliability (ICC=0.660 to 1.0). Criterion 6 (*Is the strength of recommendations provided?*) had the lowest level of reliability (ICC = 0.660).

The one criterion eliminated due to low ICC during the reliability assessment was *usability*. Previous evidence has found that usability criteria such as navigability and readability tend to be more subjective and have been shown by others to lead to low reliability scores [42,51]. This assessment adds support

to previously published studies, as only two usability criteria had ICCs greater than 0.6 and were therefore retained in the final version of the instrument.

As a result of this analysis, the new instrument can be recommended as reliable for assessing the quality of online health information, whether rated by one or two raters. It is important to place the results of this analysis within the context of other instruments available to assess the quality of online health information; however, the majority of these instruments have not been assessed for reliability. As a result, our comparison to other instruments is limited to DISCERN [48], IQT [42], QS [49], LIDA [50], and the Bernstam et al assessment of the 22 most common criteria for assessing online information [25]. The level of interrater reliability is higher for the new instrument (ICC=0.988) than for IQT (ICC=0.543) [42], LIDA (ICC=0.611) [50], QS (ICC=0.796) [42], and DISCERN (ICC=0.823) [42]. Individual criteria for the DISCERN, IQT, and QS instruments were assessed using kappa (*k*) coefficients or weighted *k* coefficients, with results ranging from *poor* (ICC=0.102) to *perfect agreement* (ICC=1.0) [25,42]. The new instrument compares favorably with these results, with a higher range of ICCs for individual criteria (ICC=0.660 to 1.0) as well as consistently higher scores for comparable criteria. For example, the new instrument shows a range of ICC scores for criteria related to the use of evidence in Web resource content of *good-to-perfect* reliability (ICC=0.660-1.0), which is higher than the range of similar criteria within both the IQT (ICC=0.553-0.899) and DISCERN tools (ICC=0.102-0.541) [42].

Limitations

The new instrument was developed, and assessed for reliability through this analysis, to assess the *quality* of online resources. However, it is important to note that the ratings of this instrument are weighted to value the use of research evidence over other components such as transparency and usability. Although this weighting reflects the priorities and purpose of the Portal (to increase access to evidence-based information about healthy aging), not all internet users may judge *quality* by the same standards. While citizens may value usability features (ie, website appeal, ease of use, accessible language, and lack of advertisements, pop-ups, and other interference [52,53]), multiple studies (including this one) have consistently reported low ICC scores for usability-related items, which supports the decision to include only two such items in the final set of items for the new instrument [42,51]. Future research is needed to establish the feasibility of validated methods for assessing usability of online resources, particularly those targeting older adults.

The data for this analysis came from ratings conducted by an established staff of trained raters. Although the ICC analysis takes into account the impact of untrained raters on assessments, ongoing analyses will be useful to verify this with a group of trainees or members of the public (eg, university student trainees contributing to the development of website content, including the rating of online Web resources).

Lastly, it is important to note that the new instrument assesses the process of resource development and not the accuracy of the information or congruency of the content with the latest high-quality evidence. In the development phase of this instrument, there was discussion about including criteria to rate the accuracy of online health information. However, our aim was to create a quality assessment instrument that was easy for anyone to use; an accuracy check requires subject matter expertise, and raters having access to the latest high-quality research and the ability to search, appraise, and interpret the

messages of this research, which was deemed inappropriate for citizen raters. The final set of items included in the new instrument values the use of high-quality evidence in resource development as a proxy for measuring the quality of claims and recommendations included in the resource. This approach has been used by others with similar types of instruments [12]. Further assessment is needed to determine if this hypothesis is true.

Implications

This analysis not only illustrates that the new instrument is a reliable tool for assessing the quality of the process for developing online health information, but also supports the decision to move to a one-rater system for assessing Web resources. A small staff of 3-4 raters independently rate resources to publish on the McMaster Optimal Aging Portal; this saves considerable time, costs, and human resources toward the production of this content. Other practical implications of this analysis include the potential for external raters (eg, health professionals or citizens) to use this instrument to independently assess or design their own high-quality online health information. Future plans include making a copyrighted version of the instrument publicly available and using the instrument and ratings to provide guidance in developing high-quality online health information with health organizations and developers of health information websites. This new quality assessment instrument was designed to have a broad application, be adaptable to assess the quality of online health information relevant to topics across the health care continuum, and is intended for multiple audiences.

Conclusions

The instrument developed and assessed in this study has excellent interrater reliability for overall rating score and good-to-excellent reliability for individual rating criteria. The instrument can be recommended as highly reliable for the assessment of online health information.

Acknowledgments

This research was possible through funding provided by the Labarge Optimal Aging Initiative at McMaster University. We acknowledge the contribution of the expert leadership team in the development of the McMaster Optimal Aging Portal: Brain Haynes, MD, PhD, FRCPC, FACMI, MACP; John Lavis, MD, PhD; Anthony Levinson, MSc, MD, FRCPC; Parminder Raina, PhD; and Alfonso Iorio, MD, PhD, FRCPC. The authors would also like to thank the research assistants who performed the Web Resource Ratings included in the analysis.

Authors' Contributions

MD coordinated writing of the manuscript with team members and finalized the manuscript for publication. SW coordinated the writing of the manuscript with team members and contributed to the final draft of paper. KR contributed to the background and discussion sections of the manuscript, conducted statistical analyses using SPSS, contributed to all drafts of the paper, and helped to finalize the manuscript for submission. KG contributed to the writing of the methods and results sections and reviewed manuscript drafts. RYN consulted on the statistical analyses, wrote components of the results and discussion sections, and reviewed all drafts. AJL contributed to the interrater reliability analysis methods, analyses of findings, and reviewed the final draft.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Medline search output for web resource rating instruments.

[[PDF File \(Adobe PDF File\), 30KB - aging_v1i1e3_app1.pdf](#)]

Multimedia Appendix 2

Web resource rating tool.

[[PDF File \(Adobe PDF File\), 63KB - aging_v1i1e3_app2.pdf](#)]

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Abbreviations

ICC: intraclass correlation coefficient

IQT: Information Quality Tool

QS: Quality Scale

Edited by G Eysenbach; submitted 18.10.17; peer-reviewed by K Smith, P Schulz; comments to author 30.11.17; revised version received 26.01.18; accepted 27.03.18; published 07.05.18.

Please cite as:

Dobbins M, Watson S, Read K, Graham K, Yousefi Nooraie R, Levinson AJ

A Tool That Assesses the Evidence, Transparency, and Usability of Online Health Information: Development and Reliability Assessment
JMIR Aging 2018;1(1):e3

URL: <http://aging.jmir.org/2018/1/e3/>

doi: [10.2196/aging.9216](#)

PMID: [31518240](#)

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Original Paper

Diabetes Online Community User Perceptions of Successful Aging With Diabetes: Analysis of a #DSMA Tweet Chat

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Abstract

Background: According to the American Diabetes Association, there are approximately 30.3 million Americans with diabetes, and the incidence is growing by nearly 1.5 million cases per year. These individuals are at particularly high risk of developing secondary comorbid conditions related to diabetes and aging. Nearly 45% of individuals aged 65 to 75 years use social media, and this number is steadily growing. The use of social media provides the opportunity to assess the perceptions and needs of this population.

Objective: The purpose of this study was to examine stakeholder perceptions of successful aging with diabetes.

Methods: This study presents a retrospective analysis of a tweet chat focused on aging with diabetes. Tweets were collected using Symplur Signals data analytics software (Symplur LLC) and analyzed for content analysis, sentiment, and participant demographics. Two authors reviewed discussion posts for accuracy of analysis.

Results: A total of 59 individuals participated in this tweet chat generating 494 tweets and nearly 2 million impressions. Most (36/59, 63%) tweet chat participants were people living with diabetes; 25% (14/59) were caregivers and advocates. Seven countries were represented in the conversation. A majority (352/494, 71.3%) of the tweets indicated positive sentiment related to aging with diabetes. Five major themes emerged from the qualitative analysis: (1) personal decline now and in the future, (2) limited access to treatment, (3) inability to provide self-care, (4) health care provider capacity to support aging with diabetes, and (5) life-long online peer health support to facilitate diabetes management.

Conclusions: Individuals with diabetes are living longer and want to be supported with specialized care and access to technology that will allow them to successfully age. Aging- and diabetes-related changes may complicate diabetes management into old age. People with diabetes desire options including aging in place; therefore, special training for care partners and health care providers who care for older adults is needed.

(*JMIR Aging 2018;1(1):e10176*) doi:[10.2196/10176](https://doi.org/10.2196/10176)

KEYWORDS

diabetes; aging; social media; Twitter

Introduction

According to the American Diabetes Association, there are approximately 30.3 million Americans with diabetes, and the incidence is growing by nearly 1.5 million cases per year [1].

The population of adults aged 65 years and older is also growing [2], and incidence of diabetes among this older population is over 25% [1]. By 2050, the number of adults in the United States aged 65 years or older will nearly double to about 83.7 million [3]. Individuals with diabetes are now living 15 years longer

than those diagnosed from 1950 to 1960 [4]. Despite the increased needs of the population, there is a lack of research focused on successful aging among individuals living with diabetes.

The normal aging process and diabetes can both contribute to functional impairment or disability. Self-management, independence, and quality of life can become more challenging and in some cases, negatively impacted, when functional impairments or disability are present [5,6]. Impairments may include sensory limitations such as hearing, vision, or touch or may include biomechanical limitations including immobility, weakness, or tremors [7-9]. In addition to sensory and biomechanical impairments, cognitive decline associated with the aging process or diabetes may complicate self-management, increasing the risk of hospitalization and hypoglycemia [10,11].

It is important to understand the perception of aging in those living with diabetes, yet there is a gap in the literature regarding how individuals currently living with diabetes view the future. Nearly 45% of individuals aged 65 to 75 years state that they use social media, and this number is steadily growing as the population ages [12]. Social media has made it possible for individuals with diabetes to engage in peer health. Peer health is defined as the interaction, education, and support offered by peers with the same condition to promote self-care [13,14]. One way that individuals engage in diabetes-related conversations on social media is through tweet chats on Twitter. Tweet chats are scheduled discussions that use a preidentified hashtag. Diabetes Social Media Advocacy (#DSMA) is a weekly tweet chat for individuals affected by diabetes that has been in place since July 2010. #DSMA tweet chat topics vary from week to week and participant stakeholders include people with diabetes, care partners, health care providers, and advocacy organizations. Analyzing discussions on social media, such as the #DSMA tweet chat, provides an opportunity for researchers and clinicians to understand perceptions on topics, such as successful aging, from various diabetes stakeholders. The purpose of this study was to determine stakeholder perceptions of successful aging with diabetes.

Methods

Sampling

A retrospective analysis of the #DSMA tweet chat focused on diabetes and aging that occurred on April 13, 2016, was undertaken. Approval from the University of Utah Institutional Review Board was sought but deemed unnecessary given the

public availability of tweets. The tweet chat consisted of 5 questions (see [Textbox 1](#)), and closing thoughts, which were posed by the #DSMA moderator.

Symplur Signals (Symplur LLC) was used to extract data during the 60-minute tweet chat and 15 minutes following the chat to capture any continued conversation that may have occurred. Symplur Signals is an analytics platform that is directly linked to the Twitter application program interface and has the capability to assign health care stakeholder designation (ie, people with diabetes, caregiver, physician, advocacy organization) based on Twitter account biographies [15]. For example, every Twitter user sets up a user profile which may indicate their profession or other identifying factors. Many Twitter users involved in the diabetes online community also state what type of diabetes they have or if they are a care partner of someone with diabetes. In addition to these demographics, the language used in tweets and geographic location of the Twitter user can be collected to further analyze demographic information.

Analysis

Various tools from Symplur Signals [15] were employed to extract health care stakeholder designation. Accuracy was determined by one of the authors (CS) by initially reviewing the health care stakeholder designation populated by Symplur Signals and making adjustments as needed to correct the information (ie, changing caregiver/advocate to person with diabetes). The health care stakeholder designation was then reviewed by a second author (MLL) to determine credibility.

Symplur Signals assigns numbers to each word in the tweet as it relates to sentiment. Scores are based on the degree of negativity (-6 through -1), positivity (1 through 6) and neutrality (0) using a proprietary natural language processing (NLP) algorithm to extract subjective words and emoticons to determine the level of negativity and positivity. Scores were reviewed by 2 independent reviewers (MLL and PMG) and adjusted as needed to address unique words and phrases that may have positive meaning but were given a negative score and vice versa. For example, NLP may misinterpret sarcasm or irony. The top tweeted negative and positive words were initially reviewed, and then tweets were examined one by one and changed to reflect the intended sentiment. Scores in these cases were discussed and agreed upon by 2 independent reviewers. The top 25 most frequently used words in the tweets were identified (see [Table 1](#)).

Textbox 1. Diabetes Social Media Advocacy questions.

- Q1. How do you define successful aging with diabetes? #DSMA
- Q2. What are your concerns about aging with diabetes? #DSMA
- Q3. How can health care providers help or hinder successful aging? #DSMA
- Q4. How can technology help or hinder successful aging? #DSMA
- Q5. How can the diabetes online community support you and your diabetes as you age? #DSMA

Table 1. The top 25 most frequently used words in the tweets.

Rank	Words	Number of tweets
1	Diabetes	81
2	Aging	58
3	Help	39
4	Tech	32
5	Complications	30
6	Successful	29
7	Good	27
8	Care	26
9	Support, technology, life	22
10	Age, hinder	21
11	Years	20
12	Time	13
13	Getting	17
14	Hope	16
15	Hcps, older	15
16	access, summer, concerns, anthem, chat	14

A content analysis of retrospective Twitter transcripts was conducted. The tweet chat transcript was downloaded and deidentified to protect identity. Tweet data were cleaned, and responses from [Textbox 1](#) questions were grouped. Data were read, line by line, by 2 independent investigators (MLL and PMG), who coded the data using an open code approach while a third author (CS) facilitated consensus to establish credibility. Themes were then developed from the codes [16]. Repeated codes, uniquely identified as retweets in social media research, were used to assess the content of the data but not to determine data saturation [17]. Quotes used in the results below were slightly altered, while maintaining the meaning of the tweet, in order to protect identity.

Results

Qualitative Analysis

There were 59 participants who generated 494 tweets with an average of 8.4 tweets per participant. In addition, 104 retweets, 110 replies, 220 mentions, 5 tweets with links, 2 tweets with photos, and 1,966,945 impressions were captured in the tweet chat. Among the participants, there was a median of 6 tweets with interquartile range of 11; thus, there was a solid group of participants who were highly active in the discussion along with several participants with 1 or 2 tweets. The conversation was dominated by people living with diabetes (36/59, 63%) and caregivers/advocates (15/59, 25%). Advocacy organizations (eg, American Diabetes Association, 3/59, 5%), media organizations (eg, news outlets, 2/59, 3%), nonhealth organizations (eg, advertising companies, 1/59, 2%), a physician (1/59, 2%), and an unidentified stakeholder (1/50, 2%) were also identified. The tweet chat was global in nature and included individuals from 7 known countries—United States of America (31/59, 53%), Canada (3/59, 5.1%), Italy (2/59, 3.4%), Sudan

(1/59, 1.7%), Philippines (1/59, 1.7%), Peru (1/59, 1.7%), and Australia (1/59, 1.7%)—and 19 unknown countries (19/59, 32%). Sentiment analysis was overwhelmingly positive (71.3% [352/494] of tweets) (see [Figure 1](#)).

The qualitative analysis provided unique insight into how individuals with diabetes view successful aging. The analysis resulted in 5 major themes: (1) personal decline now and in the future, (2) limited access to treatment, (3) inability to provide self-care, (4) health care provider capacity to support aging with diabetes, and (5) life-long online peer health support to facilitate diabetes management.

Personal Decline Now and in the Future

Participants overwhelmingly felt that successful aging was the process of getting older without feeling sicker. Feeling sicker was identified as having diabetes-related complications or feeling more tired or older than chronologically similar peers without diabetes. Some participants felt that diabetes-related complications might be inevitable, while others were already experiencing diabetes-related complications.

That no complications ship has sailed, my friend. And I'm still aging, still here, still fighting the good fight.

In general, the act of aging at all with diabetes was viewed positively.

Aging with diabetes is automatically a success, living without complications is a bonus. Aging at all beats the alternative.

Individuals were optimistic about the idea of living into old age, noting that they would do the best they could in order to age successfully. Tactics to achieve this included staying positive and addressing challenges as they came. While some participants

were looking forward to aging in the future, some participants noted that they had already aged successfully.

Successfully aging is getting a Joslin 50-year medal and still appreciating the fact that you're alive and can still laugh.

Limited Access to Treatment

Participants wanted to be able to access similar treatments, including technology, into old age that they are accustomed to now. Participants expressed worry about access to care as they aged, including insurance coverage and affordability. Specifically, participants were concerned with access to medications (with an emphasis on insulin), medical supplies (eg, glucose strips), medical devices (eg, insulin pump, continuous glucose monitor), and lab work.

The way things are going, insulin will eventually cost a zillion dollars a year.

Participants identified the current coverage for older adults (eg, Medicare) relating to technology as undesirable and unable to meet their diabetes management needs.

If people have access to tech and then they can't afford it anymore or it's not covered, it's a problem.

Addressing barriers to access was viewed as important for being able to successfully manage diabetes into old age.

Inability to Provide Self-Care

Participants expressed positive sentiment about using technology that may help them if they should experience the usual changes in aging, such as hearing, vision, and cognitive changes (eg, insulin pens that indicate the time of the last injection to help with forgetfulness) but were concerned that they may lose the ability to continue their current treatment due to these age-related changes. These concerns were focused on inability to visualize the screens on glucometers or insulin pumps, push buttons on insulin pumps, and draw up and inject insulin.

Loss of independence in diabetes management raised concerns. Participants desired the ability to continue their own self-care, but they were also aware that normal age-related changes may limit them in the future. These limitations included changes in

vision, strength, and cognitive function. As such, some participants worried about their future inability to address the physical and cognitive tasks related to managing their diabetes. These tasks included checking glucose, administering insulin, and making proper decisions about insulin dosing.

Changes in independence raised concerns about burdening or becoming reliant on others for diabetes self-care. Some participants worried that they didn't feel they could trust another person to care for their diabetes with the same diligence as they did for themselves. One individual overtly stated that they were fearful of the diabetes care they would receive in a long-term care facility.

Health Care Provider Capacity to Support Aging With Diabetes

Participants desired health care providers with dual expertise in aging and diabetes. There was concern that some providers wouldn't have the knowledge to distinguish the difference between diabetes-related complications and normal functions of aging. Further, participants stressed that the time since diagnosis is often much longer in someone with type 1 diabetes compared to type 2 diabetes, necessitating a workforce who understands this population.

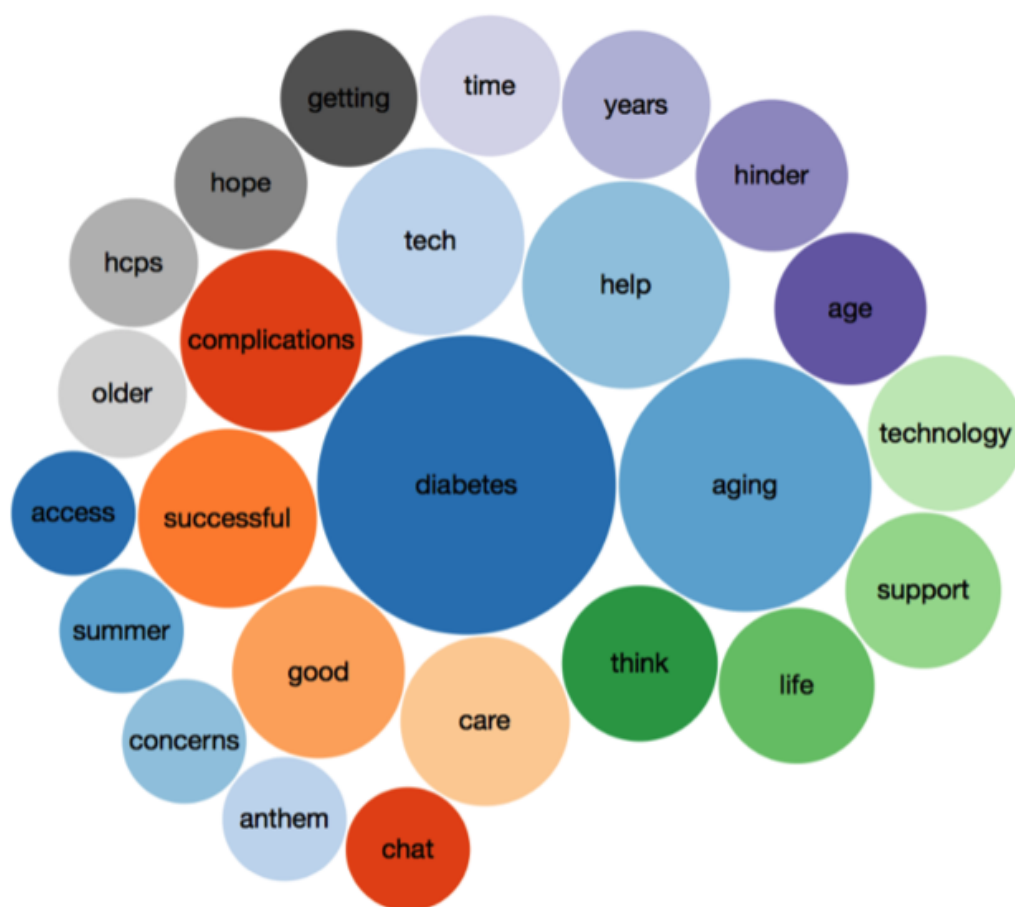
In my experience, few doctors know how to treat patients with type 1 diabetes, especially those who have lived with the disease for decades.

Those with diabetes for decades felt there was much they could teach health care providers about longevity with diabetes.

Concern was expressed over how individuals are being approached by health care providers now and how this would impact successful aging. The importance of receiving good care from health care providers today, while participants were younger, was viewed as important in aging with diabetes. Participants desire care that is tailored to their unique needs including diabetes type.

[Health care providers] are not geared to see how individual needs vary, there is not a one size fits all treatment.

Figure 1. Sentiment over time.



Some participants had been discouraged by health care providers using negative approaches such as scare tactics. Participants wanted their health care providers to use positive approaches, fostering hope in their ability to simultaneously manage their diabetes and age successfully.

Life-Long Online Peer Health Support to Facilitate Diabetes Management

Participants highly valued their relationship with others in the diabetes online community. There was consensus in participants wanting to continue their relationships with one another as they aged, “growing old together.”

The diabetes online community will always be there when I have ups and downs, highs and lows, good days and bad days.

It was recognized that Twitter may not be available in the future. Participants noted that they would seek out other technology platforms. Some participants anticipated they may not be able to engage in technology as an older adult due to age-related changes, such as in dexterity or vision. In these instances, participants planned to regress to handwritten letters in order to maintain connection with their peers.

Discussion

Principal Findings

Age-related decline coupled with diabetes-related complications are concerning to people with diabetes. These aging- and diabetes-related changes can impact the immediate family and care partners of people with diabetes. Recognizing the complex nature of the impact of diabetes, not just on one person but on an entire family, is crucial to improving treatment for people with diabetes transitioning from middle age to older adulthood.

Transitioning from middle age to older adulthood with diabetes is not well understood. Current guidelines suggest that targeted education on the transition from adolescence to young adulthood should begin at least 1 year before high school graduation [18]. During this developmental life phase, individuals transition to young adulthood with increasing independence as the parent care partners decrease support. While the aging process varies by individual, establishing transition education and processes may also be helpful to support the transition from middle adulthood to older adulthood. Transition education needs in older adulthood include understanding the changes from commercial insurance to federally funded insurance, differentiating changes related to normal aging and diabetes complications, and navigating self-care amid possible comorbid conditions, such as cognitive decline. As older adults establish wills, powers of attorney, and attend to other legal matters, older individuals with diabetes may want to identify potential care

partners (eg, spouses, children) who can become educated on diabetes management skills. Being proactive in educating potential care partners before it is necessary can ease transition of diabetes care responsibility if the person with diabetes becomes dependent on others in the future.

Many older adults are currently using diabetes-related technology [19,20], and this number will likely grow. Participants expressed desire to continue use of insulin pumps and continuous glucose monitors into old age as long as they were able. Access to diabetes technology may be limited by insurance provider, resulting in some individuals needing to change their current diabetes management strategies. Normal age-related changes in vision, extremity function, and cognition may create challenges for continued use of diabetes-related technology. Technology should support people with diabetes across all age groups and be designed to accommodate age-related changes in vision, hearing, and dexterity wherever possible. Access to medications may also become problematic. For example, those on brand insulin may experience challenges in coverage or cost, resulting in the use of generic and less biologic insulin.

Health care providers should tailor care to meet the needs of individuals with diabetes as they age. Therefore, it is important that health care providers understand the aging process, how aging impacts diabetes, and how to best care for older adults with diabetes. Individuals with diabetes are living longer [21], and their care and comorbidities may be very different depending on diabetes type and other health factors. There is an urgent need to increase the health care provider workforce having expertise in geriatrics and gerontology in order to meet the unique care needs of older adults with chronic conditions, such as diabetes. The Institute of Medicine's 2008 *Retooling for an Aging America: Building the Health Care Workforce* reported that medical, nursing, pharmacy, and other health care provider programs contained very little geriatric-specific content [22]. At the time of the report, less than 1% of nurses and pharmacists specialized in caring for older adults, and there was only 1 geriatrician for every 2546 older adults [22]. With the older adult population increasing and with a higher proportion of older adults living with diabetes, it is imperative that health care providers receive education about caring for older adults with chronic conditions such as diabetes and seek specialized training in geriatrics.

The diabetes online community provides emotional support and knowledge [13,23] and is associated with better glycemic levels, self-care, and quality of life [14]. We found that individuals planned to use technology and other means to remain connected

to others in the diabetes online community. Loneliness in older adulthood can negatively impact health [24,25], and addressing psychosocial needs is an important factor to successful aging [26]. Having a large support network, such as the diabetes online community, may provide health benefits as individuals with diabetes age. Older adults who are limited by location or geography may still be able to use the internet to connect to online communities and engage with peers [27]. Older adults are adopting internet usage at a pace faster than other groups, and online social communities for older adults are steadily growing [27,28]. Social support and connectedness may be the answer to promoting optimal self-management support for older adults with diabetes. Caregivers of older adults in the future may need training to support social media or other technology use.

Limitations

Due to the nature of data collection on Twitter and Symplur Signals, we are unable to obtain more precise demographic information such as age, race, and gender. However, tweets emphasized the desire for a health care provider workforce knowledgeable about type 1 diabetes, suggesting some of the individuals participating in the tweet chat analyzed were affected by type 1 diabetes in some way. Individuals accessing online resources such as Twitter tend to be more active in self-care. Therefore, our study sample may not be representative of the general population of individuals aging with diabetes. More research is needed to understand aging needs of individuals with both type 1 and type 2 diabetes.

Conclusions

All individuals experience changes in health related to aging; however, those with diabetes may experience complications that might exacerbate these changes. In this study, individuals with diabetes expressed a desire to prolong independence and age in place. Individuals with diabetes need access to and insurance coverage for technology and medication at the same or higher levels into older adulthood to facilitate positive diabetes management. In addition, dual training in geriatrics and diabetes would increase health care provider ability to differentiate normal age-related changes and diabetes complications, thus providing specialized support to people with diabetes that is currently limited. Finally, participants expressed a desire for education to support care partners and access to social support off- and online. Having all stakeholders take active steps toward the successful aging of individuals with diabetes will promote patient-centered care and may enhance health.

Acknowledgments

This work was presented at the Stanford Medicine X Conference (see [Multimedia Appendix 1](#)).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Video presentation link.

[[PDF File \(Adobe PDF File\), 11KB - aging_v1i1e10176_app1.pdf](#)]

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Abbreviations

DSMA: Diabetes Social Media Advocacy

NLP: natural language processing

Edited by J Wang; submitted 21.03.18; peer-reviewed by A Ng, T Oser; comments to author 12.04.18; revised version received 10.05.18; accepted 10.05.18; published 22.06.18.

Please cite as:

Litchman ML, Snider C, Edelman LS, Wawrzynski SE, Gee PM

Diabetes Online Community User Perceptions of Successful Aging With Diabetes: Analysis of a #DSMA Tweet Chat

JMIR Aging 2018;1(1):e10176

URL: <http://aging.jmir.org/2018/1/e10176/>

doi: [10.2196/10176](https://doi.org/10.2196/10176)

PMID: [31518231](https://pubmed.ncbi.nlm.nih.gov/31518231/)

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Original Paper

Understanding Why Older Adults With Type 2 Diabetes Join Diabetes Online Communities: Semantic Network Analyses

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Abstract

Background: As individuals age, chronic health difficulties may disrupt physical and social well-being. Individuals can turn to online communities to interact with similar peers, which may help buffer negative effects resulting from health difficulties.

Objective: This study investigated the reasons that older adults join a diabetes online community to better understand the specific resources that are being sought.

Methods: We used semantic network analyses to categorize the reasons participants provided for joining a community during the sign-up process.

Results: The most frequent reasons for joining were to seek information about their health condition, to help with self-management of health difficulties, for feelings of informational and social support, and for having a community with whom to share. Women were more likely to go online for sharing and companionship as well as for information and social support reasons, whereas men were more likely to go online for general information and self-management reasons.

Conclusions: This study shows the reasons older adults seek to join a diabetes online community: for increased information and support regarding chronic health difficulties. Practitioners may want to consider ways to promote access to online communities among their older patients as a source of health information and a resource to provide a sense of community.

(*JMIR Aging* 2018;1(1):e10649) doi:[10.2196/10649](https://doi.org/10.2196/10649)

KEYWORDS

online community; diabetes; health information; health support; chronic health difficulty; self-management; social support

Introduction

Background

Across one's lifespan, social interactions with same-aged peers—who are more likely to share attitudes, values, and interests—are important [1]. But barriers to mobility resulting from health difficulties may limit social contact [2,3]. Online communities, defined as collectives of voluntary members who

share common interests or experiences and who interact primarily over the internet [4], may offer older adults, or people over age 65, an opportunity to engage with peers regardless of physical ability and location [3]. Online communities specifically for older adults are steadily growing [3], as increasing numbers of older adults have broadband access, use mobile phones, and are actively increasing their use of the internet [5] at the fastest rate of any population [6]. The potential

for older adults to benefit from the internet for health information seeking [7,8], managing chronic conditions [7,9,10], interacting with similar peers [3], and engaging in online communities is starting to be recognized [11,12]. However, less attention has been paid to understanding older adults' perceived benefits of joining online health communities, and few studies have directly examined older adults' reasons for joining online communities.

In this study, we examined the reasons that older adults provided for joining an online community during their initial registration, to shed light on their needs and goals. The socioemotional selectivity theory suggests that older adults, due to perceived limitations on time and energy, are more likely to invest time *maintaining* quality social connections and balancing health states relative to forming *new* relationships and seeking *new* information [13]. However, it is unclear whether this distinction holds for online communication that removes physical barriers, potentially making it easier to interact, and for topics that are highly self-relevant such as those pertaining to one's health [14]. Thus, older adults' motivation for joining online communities may involve both forming new relationships and seeking information. Previous studies have shown that online communities may provide a space for older adults to seek health information, self-management strategies, and peer support and interaction [3,15,16]. We add to this literature by identifying reasons that older adults join online communities.

Health Information Seeking

Although older adults receive health information from their primary care providers, seeking supplementary health information is still one of the most popular online activities [6], especially if the information given by health professionals is difficult to understand [9]. Some members of online communities report health care providers as the primary source of information [17], but participation in online communities can supplement that information through observing and interacting with individuals who have similar health conditions [9]. Older adults may find that health information in online communities differs from that of general websites because the information shared in online communities is often tailored to the unique needs of the group and the information may be more acceptable to receive from people with similar needs or goals [15]. The information may also be easier to understand, based on their social connections' recent experience, and is readily available content [14].

Moreover, an online environment allows older adults to send and receive information to and from others asynchronously, thus reducing any restriction on time and mobility for receiving information about their condition [14], which may increase a sense of control [18]. In light of these findings, which suggest gathering general information regarding chronic health conditions is a key reason that older adults go online [19-22], we expect to find that one reason older adults join online health communities is to obtain general information.

Self-Regulation and Management

More specifically, however, older adults likely join online communities to seek information related to self-management

of a chronic health condition, which has been shown to contribute to older adults' quality of life [21,23-25]. During times when primary providers are unavailable, older adults may need guidance in self-management of their health condition and may turn to the online community to receive that support [3,9]. People tend to trust others with shared experiences; the information shared in online communities may positively influence health behaviors [9]. One example would be community members co-constructing health knowledge and working together to fill gaps in health information to better understand their condition [3,26]. Therefore, we expect that individuals search for online communities to seek self-management information.

Peer and Social Support

In addition to being a valuable resource for seeking health information, social support for chronic health difficulties may be another reason for joining online communities [27]. Receiving social support is particularly important for an individual's well-being, by reducing stress and increasing adherence to treatment plans [15]. Low social connectedness is consistently associated with poorer health outcomes [28,29]. Those interacting in online communities may have more assistance in monitoring their condition and have a greater pool of self-management support resources [30,31].

Social support is especially valued when it comes from individuals with similar experiences [32]. A crucial benefit of online communities is that self-disclosure about chronic health conditions is perceived to be easier than in face-to-face discussion [3]. Allowing one to see their experiences as normal and receive praise for successful self-management, as well the confidence boost to reveal certain experiences to their provider is also an advantage [14]. In fact, greater social involvement online may lead to better self-management, physical health, and emotional well-being [9,28]. Although participation in online communities may not cure chronic health difficulties, the support from social connections may help improve the quality of life for older adults [27], thus it is essential to thoroughly understand the types of support being shared and received in online health communities. As previous studies have shown, individuals often go online to receive support for the information received from providers [19,21,22,33] and to receive social support to reduce adjustment difficulties that often coincide with chronic health difficulties [34-38]. Therefore, we expect individuals going to online communities for support will identify and cite reasons related to (1) information seeking and (2) maintaining contact with similar peers.

In this study, we investigated three general areas that older adults may offer as reasons they joined an online health community: (1) health information seeking, (2) self-regulation, and (3) social support. We drew on data from one of the largest diabetes online communities in the United States, the Diabetes Hands Foundation (DHF). The DHF was a nonprofit organization that "connects, engages and empowers people touched by diabetes." At this time, the DHF has resolved and TuDiabetes is now part of the *Beyond Type 1* organization. Leaders of DHF provided a de-identified dataset of the initial registration information collected when a new member joined

the English-speaking language community (TuDiabetes.org). Based on literature reviewed above, we used semantic network analyses to confirm and further refine the reasons given for joining diabetes online communities in the areas of information-seeking, advice on self-management, and maintaining peer connections and receiving support from peers.

Methods

The dataset included limited demographic information including age, sex, and diabetes type (I or II). The reason for joining was obtained from an open-ended question, “Why did you want to join?” Data for this study were obtained between June 12, 2007, and September 1, 2014, after which TuDiabetes began using a new database and no longer asked this question on joining. The dataset was retrieved in December 2014. Permission for this study was obtained from the Institutional Review Board at Northwestern University.

Inclusion Criteria

Inclusion criteria for the study were that members had to be at least 65 years old and have type II diabetes. Age was reported by members at sign-up. The database contained 34,797 records: 30,248 participants were younger than 65 years old, 435 had type I diabetes, 49 had pre/no diabetes, and 2096 did not specify their age. The final sample included 1969 individuals, aged 65 and over, with type II diabetes.

Ethical Approval and Consent

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent was obtained from DHF for all participants included in the study.

Procedure

We analyzed the unstructured free-text field responses that members provided on joining, in two phases.

Phase I

First, we examined the content of each response using semantic network analysis, which assesses the frequency of word co-occurrences [39]. The more frequently that two words co-occur, the more strongly they are related (as reflected in the pair’s “weight”). Centrality of a word, or the number of connections any word has with all other words, was also measured to reveal the importance of a concept in the dataset used (“weighted degree”). This approach has the added benefit of allowing us to produce a visual representation of the relationships among the concepts. We used ConText, which was created to conduct text and network analysis in an automated fashion for researchers in the digital humanities and social sciences [40], to construct the semantic network matrices, using the top 100 word pairs (co-occurrences of the words). To test intercoder reliability, a subsample of at least 10% of the full sample is required to be coded independently by independent coders [41]. In this study, a subsample of the top 26.52% word

pairs (weight of 7077/26,685), or the top 100 word pairs, each with a weight of 25 or more, were coded by 3 independent coders. A weight below 25 meant that the word pair had occurred less than 0.10% (25/26,685) of the time, rendering those word pairs less significant. We then imported the top 100 word pairs into Gephi, a software for graph and network analysis that displays large networks for interactive exploration [42] and UCINET, which is used for graphical representation of network analysis [43] to run the matrix files in order to display the graphs and calculate each word’s centrality. This provided us with information on the connections among concepts within each open-ended response, and therefore, we referred to this as an item analysis.

The output of the network analysis can be seen in [Figure 1](#) (for all pairs) and [Figure 2](#) (top weights only). The strength of the relationship between word pairs is denoted by line thickness. For example, the word pair “Diabetes information” (n=485) co-occurred most frequently, signified by the thickest line in [Figure 2](#). Each of the top 12 word pairs (diabetes-information, support-information, help-information, learn-information, other-information, more-information, share-information, how-information, control-information, knowledge-information, learn-diabetes, and information-sharing) were related to sharing of information, giving an aggregated weight of 2762/7077, which is approximately 39.02% of the top 100 pairs.

Phase II

Borrowing the approach used by Wang et al [44] and taking into account the output from the semantic network analysis (Phase I), we identified broad categories into which the word pairs could be coded. We established the broad categories to provide an orienting framework to organize the word pairs, in order to have a way to consistently categorize the common ways that individuals use the DHF. We coded pairs ([Table 1](#)) as general information, self-management, share/support/companionship, informational support, and social support. Pairs were coded as:

- general information if they indicated that the new member sought advice, referrals, or knowledge [19,21,33]
- self-management if the word pairs indicated older adults going to the DHF for help with activities such as diet, self-regulation, pump, or medicine [23-25]
- share/support/companionship if the word pairs indicated anything involving two or more people and did not include words such as support, help, or advice [25,34,35]
- informational support if the word pairs were informational in nature and included words such as support, help, or advice without mentioning another person [21,22]
- social support if the word pairs were social in nature and included words such as support, help, or advice while mentioning another person [34,35,45]

We coded the top 100 word pairs (a weight of 7077/26,685) to determine their relative frequency. Word pairs were coded independently by 2 raters, yielding adequate reliability (Cohen’s kappa = .73). A third rater resolved disagreements.

In sum, we conducted two sets of analyses on these words used by older adults: item-level and person-level. Item-level analyses

Table 1. Definitions of the coded categories and word pair examples.

Category	Definition	Actual word pair examples	References
Information	knowledge related	diabetes information; disease information; learn how	Bartlett & Coulson, 2011; Greene et al, 2010; Kaufman, 2010
Support (informational)	“support,” “help,” “advice,” without referencing another person	support how; information help	Menefee et al, 2016; Kaufman, 2010
Support (social)	“support,” “help,” “advice,” referencing another person	support people; help people	Crotty et al, 2015; Dale et al, 2012; Nicklett et al, 2013
Share/companionship	“share,” and involve other people	information community; share support; friendship information	Crotty et al, 2015; Strom & Egede, 2012; Vassilev et al, 2013
Self-management	diet, self-regulation, complication, blood, etc; pump and instrument; medicine	control better; treatment information; recipes information; pump information; diabetes pump; understand Super Bolus; insulin questions	Bodenheimer et al, 2002; Quinn et al, 2011; Vassilev et al, 2013
N/A	not applicable	other more; other how	

Results

Item analyses (Table 2) showed that, among the most highly weighted 100 word pairs (ie, those having weight ≥ 25), 45.54% (3223/7077) reflected general information seeking. However, slightly more than half of the pairs fell into more specific categories. Specifically, 13.86% (981/7077) of the word pairs belonged to share/support/companionship, 16.83% (1191/7077) were categorized as expressing a desire for self-management (including medicine and pump), and 15.84% (1121/7077) and 5.94% (420/7077) indicated informational support and social support, respectively. Only 1.99% (141/7077) of the word pairs did not fall into one of our categories (see Table 2).

Person-level results are shown in Table 3. We found that 29.20% (574/1969 members) indicated that they joined the DHF to seek information but provided no additional information. On the other hand, the clear majority of new members provided information that could be more specifically coded. A large proportion of individuals, 18.10% (356/1969 members), stated that they joined the DHF for sharing/support/companionship purposes; 18.50% (365/1969 members) for information related

to self-management (including pump and medication); 7.90% (155/1969 members) for informational “support” alone; 5.60% (111/1969 members) for social “support” alone; 3.65% (72/1969 visitors) gave responses that were not applicable; and 17.05% (336/1969 members) did not give an answer.

In addition to examining the percentage of older adults that endorsed the five categories or reasons for going online and interacting within the DHF, we also were interested in exploring whether older adult men and women in this sample differ in the rates that they endorse their respective reasons for joining the DHF. A chi-square test was run to determine whether men and women in this sample endorsed the reasons for joining the DHF at similar rates. Older adult men and women did not endorse each of the five reasons for joining the DHF at the same rates: $\chi^2_4=16.172$ ($N=1559$), $P=.003$. As seen in Table 4, more older men than women in this sample endorsed the general information (41% men vs 33% women) and self-management categories (24% men vs 23%), whereas more older women than men endorsed the share/support/companionship (21% men vs 24% women), information support (8% men vs 12% women), and social support categories (6% men vs 8% women).

Table 2. Categories of word pairs ($N=7077$).

Category	n (%)
General information	3223 (45.54)
Other/Uncategorized	141 (1.99)
Self-management	1191 (16.83)
Share/Support/Companionship	981 (13.86)
Support (informational)	1121 (15.84)
Support (social)	420 (5.94)

Table 3. Reasons members gave for joining TuDiabetes (N=1969).

Category	n (%)
Health information seeking	575 (29.20)
Other/Uncategorized	408 (20.72)
Self-management	364 (18.50)
Share/Support/Companionship	110 (5.60)
Support (informational)	356 (18.10)
Support (social)	156 (7.92)

Table 4. Cross-tabulation of gender by category (N=1559).

Category	Gender ^a , n (%)	
	Men (n=789)	Women (n=770)
General information	323 (41.94)	251 (32.59)
Self-management	186 (23.57)	179 (23.25)
Share/support/companionship	168 (21.29)	188 (24.42)
Information support	64 (8.11)	89 (11.56)
Social support	48 (6.08)	63 (8.18)

^a $\chi^2=16.172$ (df=4); $P<.01$.

Discussion

Principal Considerations

Even with barriers to social contact in older age such as limitations on mobility as the result of health difficulties, online communities may be one way for individuals to have social contact regardless of time, location, or physical ability [2,3]. Engaging with peers online may be of particular importance as individuals, especially those experiencing chronic health difficulties, have an increasing need for information related to prevention, diagnosis, and treatment. Online communication may offer a viable option for dispersing information related to condition management [3,9]. In fact, the study's results are in line with previous findings that older adults seek information online [6,14]. Not all individuals in this study who used the online community specified the type of information they sought. However, among those who did, there were several reasons specified: to seek information about their health condition, to help with self-management of health difficulties, for feelings of informational and social support, and for having a community with whom to share.

The results from this study add to the literature in a several ways. First, previous studies have shown that older adults do use online communities to obtain health information related to chronic conditions [6,14]. In order to understand diabetes patients' use of online resources to seek health information, prior studies have frequently used interviews [46-48] and surveys [49,50]. Even in situations where they used content analysis, researchers performed only traditional quantitative content analysis [12]. Supplementing traditional quantitative content analysis with semantic network analysis as the current study did, allows for examination of users' online information seeking behavior from a macro perspective. This method can

reveal the relations among different words. In this study, we were able to more precisely specify, that for diabetes, older adults are motivated by the goal of obtaining information about medication and other self-management procedures. Additionally, previous studies have shown that having an online community of similar others may contribute to feelings of support for older adults [15,27]. Our findings add to the literature by showing that older adults hope to gain support, both informational and social. A particularly exciting finding is that the older adults in this sample indicate they are going to the online community for sharing and community purposes, suggesting that in addition to acting as a health information source, online communities may be one way that older adults are able to maintain feelings of community with similar others. Interestingly, it may be the case that older adult men and women endorse the reasons for going online at different rates. Our exploratory analyses show that men were more likely than women to provide reasons related to general information and self-management, whereas women were more likely to provide reasons related sharing, personal support, companionship, information support, and social support. These results may suggest that men are more likely to gather information to help manage a chronic health condition, while older adult women may be more likely to maintaining a sense of community or support while dealing with a chronic health condition. Future studies should further examine differences between older adult men and women, as they may be able to provide support to show consistent or systematic differences in the reasons that older adult men and women join online communities.

The results of this study do not appear to fully support the socioemotional selectivity theory [13], in that older adults in this study appeared to be motivated by obtaining information and by forming new social ties, rather than motivated by maintaining quality social connections and balancing health

states. It could be that online health communities provide an exception to the theory because it is easier to form relations and gain information online without limitations on mobility and because health information is critical to well-being. It remains unclear, however, whether relations are maintained over time through these communities. A theory that might help to explain our results and that may be especially applicable when thinking about online communication or joining online communities is the Motivational Theory of Lifespan Development. This theory suggests that when individuals age, primary control, or the ability to influence environmental outcomes declines, increasing the need for secondary control strategies to maintain capacity for pursuing adaptive goals [51]. It could be that older adults' use of online communities offers a new type of secondary control strategy for older adults with chronic illness, one that helps them maintain striving for their primary goals related to health and social contact.

Future Directions

In general, the data show that both information and social support are key reasons why older adults join online health communities. More work is needed to examine the interactions between obtaining and using health information on the one hand and feeling socially connected to similar peers on the other. Past work has shown that high levels of engagement in diabetes online communities is associated with better glycemic levels, diabetes self-care, and health-related quality of life [52]. The role of peer relationships in online communities remains a key question for future research.

Limitations

There are several limitations to our study. First, we relied on a naturalistic dataset with an open-ended question on reasons for joining that was likely interpreted differently across individuals and that did not provide an opportunity for follow-up questions when general responses were provided. In addition, we did not obtain information on continued use of the online community or on community members' income or education levels, both of which are related to online use [3]. However, the goals of

the study were not to examine continued use of the community, but rather to provide insight into the reasons why older adults joined a well-known online health community. With a basis from which to draw, in the future we will examine whether older adults continue to use the online community for these same reasons.

Additionally, we must consider the data reported here in light of the growth of social media use in recent years, that participants could have increasing alternatives for online communities. However, according to the Pew Research Center, Twitter use today remains very low among older adults (8%). While Facebook use is higher (41%), the majority of older adults do not use it for a specific purpose [53]. Although news feeds are a primary reason for using Facebook across ages, little is known about the likelihood of older adults' use of Facebook for diabetes support. It is possible that growth in the memberships of other diabetes online communities could show similar patterns of reasons for joining as those reported in this study.

Conclusions

Our findings suggest that older adults seek online communities for specific types of information regarding their chronic health conditions. As such, when designing an online community for use by older adults, it should be created so that it is easy for individuals to seek information from and share information with similar others, especially as it relates to medications and other self-management practices (technology tools). In addition, the results show that older adults seek online communities for social support. While older adults may be given sufficient health information from their primary care provider, they may find it useful to connect with similar others to better understand the information and how to apply it to their condition [9,16,17]. Thus, online communities should be designed with sharing and community purposes in mind, so that beyond being a site only for seeking information, the online community provides spaces for older adults to share personal stories, both success and struggles, and receive words of support from their peers who may understand them best [47].

Acknowledgments

We would like to thank the Diabetes Hands Foundation for sharing their data with our research team. This work was supported by the National Science Foundation (NSF GRFP 1650042).

Authors' Contributions

JAL participated in interpreting the analyses and drafted the initial manuscript and revisions. PMG conceived of the initial idea for the study, gained access to a dataset, participated in performing and interpreting the analyses, and helped develop the manuscript. CLH participated in performing and interpreting the analyses and helped draft the Methods and Results sections. LMSM conceived of the initial idea for the study, participated in performing and interpreting the analyses, and helped develop the manuscript and subsequent revisions. All authors read and approved the final copy.

Conflicts of Interest

None declared.

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Abbreviations

DHF: Diabetes Hands Foundation

Edited by J Wang; submitted 29.03.18; peer-reviewed by K Colorafi, JN Wang; comments to author 17.04.18; revised version received 11.05.18; accepted 29.05.18; published 28.06.18.

Please cite as:

Lewis JA, Gee PM, Ho CLL, Miller LMS

Understanding Why Older Adults With Type 2 Diabetes Join Diabetes Online Communities: Semantic Network Analyses

JMIR Aging 2018;1(1):e10649

URL: <http://aging.jmir.org/2018/1/e10649/>

doi: [10.2196/10649](https://doi.org/10.2196/10649)

PMID: [31518243](https://pubmed.ncbi.nlm.nih.gov/31518243/)

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JMIR Publications
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