

Caring in the Information Age: Personal Online Networks to Improve Caregiver Support



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ABSTRACT

Background

It is becoming increasingly important to find ways for caregivers and service providers to collaborate. This study explored the potential for improving care and social support through shared online network use by family caregivers and service providers in home care.

Methods

This qualitative study was guided by Rogers' *Theory of Diffusion of Innovations* [NY: Free Press; 1995], and involved focus group and individual interviews of service providers (n = 31) and family caregivers (n = 4). Interview transcriptions were analyzed using descriptive, topic, and analytic coding, followed by thematic analysis.

Results

The network was identified as presenting an opportunity to fill communication gaps presented by other modes of communication and further enhance engagement with families. Barriers included time limitations and policy-related restrictions, privacy, security, and information ownership.

Conclusion

Online networks may help address longstanding home-care issues around communication and information-sharing. The success of online networks in home care requires support from care partners. Future research should pilot the use of online networks in home care using barrier and facilitator considerations from this study.

Key words: home care, social support, continuity of care, diffusion of innovation, communication, online networks

INTRODUCTION

Older adults are living longer with multiple chronic conditions and turn to family members/friends for support, sometimes from a distance.⁽¹⁻³⁾ Nearly all (98%) persons receiving formal home-care services in community settings also receive support from a family caregiver.^(4,5) While there are rewarding aspects associated with providing care,^(6,7) it is well documented that caregivers are at risk for negative health outcomes, both physically and psychologically.⁽⁸⁻¹⁰⁾

Care provision is complex for both service providers and caregivers. Service providers report poor communication, coordination, and continuity of care.^(11,12) Caregivers struggle with inadequate social support, compassion fatigue, and negative impacts on their workplace performance evidenced by reduced productivity, increased absenteeism, and reduced ability to advance in their careers.⁽¹³⁻¹⁷⁾ These issues may have a detrimental impact on the quality of care that caregivers and service providers are able to provide. Finding ways for caregivers and service providers to collaborate to optimize outcomes for families and older adult home-care clients is critical. In addition to mitigating negative impacts where lack of support exists, strong caregiver and service provider relationships produce benefits including better competence, confidence, and continuity of care.^(11,12,18,19) Relationships between service providers and caregivers can be challenging due to time constraints and issues with role negotiation.^(20,21) Technology-based communication tools may help address concerns related to information-sharing between caregiver and service provider care systems, and provide social support for caregivers.⁽²²⁻²⁵⁾ Online networks (e.g., Tyze, CareZone) have been created to support caregivers and their friends and families to coordinate care, share information, and communicate about care situations. They include a range of tools (e.g., calendar, scheduling, file storage) that can be accessed by family members using computers, tablets, and mobile devices.

Perceptions about use of technology by family caregivers in health-care settings have received some attention.^(26,27)

Interventions such as video-teleconferencing, online support groups, and online education sessions have been conducted with caregivers showing favourable results.^(22,28-33) However, less is known about technologies aimed at enhancing contact between service providers and caregivers in a home-care setting.^(26,33)

The objective of this study was to explore service providers' and caregivers' views on the benefits, barriers, and facilitators to participating in a shared online network in the home-care setting. We used Tyze Personal Networks (Markham, ON) as an example of a tool that can facilitate online communication, information sharing, and support within a caregiving situation. Tyze provides a way for people to make appointments on a shared calendar, to share documents, to store important information, to send messages and create tasks, as well as to post stories and photos. Privacy is maintained by limiting who has access to documents in the network.⁽³⁴⁾ The networks cannot be searched and there is no advertising on a Tyze network.

We examine how service providers could be engaged to become actively involved in these types of innovative online networks with family members.*

METHODS

Theoretical Framework

This study was guided by Rogers' *Theory of Diffusion of Innovations*, which identifies factors influencing whether an innovation will be adopted by intended users,^(35,36) including stages of innovation adoption, adopter characteristics, and important considerations at each stage.⁽³⁶⁾

An innovation is more likely to be adopted if it is perceived to possess these characteristics: relative advantage (compared to current option); complexity (easy to use); trialability (can this innovation be tested before committing?), observability (are the benefits of use obvious?); and compatibility (with users' values/needs/workflow?).⁽³⁶⁾ Due to the innovation's infancy and the importance of gauging intended users' perceptions of the innovation prior to full implementation, this study took place during the knowledge stage. According to Rogers, when encouraging innovation adoption, research efforts may be focused on proliferation of both awareness and how-to knowledge.^(36,37)

Study Setting, Design and Recruitment, Sample

This qualitative interview study was conducted in Ontario, Canada where home-care services and long-term care placement are coordinated by Community Care Access Centres (CCACs). CCAC case managers conduct admission and follow-up assessments that guide care planning and referrals to those providing direct services (e.g., visiting nurses, rehabilitation therapists, personal support workers) who work for independent private or non-profit agencies.

Purposive sampling^(38,39) was used to recruit caregivers of home-care clients and service providers, with interviews taking place over a four-month period. Participants were eligible if they were computer literate and available during the study period. Service providers were excluded if they were non-English speaking or were not adequately computer literate, based on ability to use e-mail. Caregivers were recruited through case managers using a two-phase recruitment process, where case managers were asked to identify caregivers eligible for the study and contact them via telephone/in-person to provide study information. With consent, the researcher contacted interested caregivers via telephone to provide detailed study information, gain verbal consent to participate, and determine the caregiver's preferred method of participation (face-to-face, focus group interview or phone-interview). Caregivers were eligible if they identified as the "primary caregiver" (defined as a caregiver who spends the most time assisting or caring for the care recipient) for a home-care client and had access to the Internet and a computer. Caregivers were excluded if they met the following criteria: 1) non-English speaking; 2) insufficient computer literacy; 3) did not have access to a computer with audio; or 4) currently involved in another caregiver intervention study. Service providers from three agencies were interviewed in five focus groups, based on availability and convenience (groups ranged from two to nine participants). One focus group interview was conducted with case managers. Four caregivers of older adults receiving home-care services who identified as the primary caregiver were also interviewed individually (one face-to-face, three by telephone) to see how their perspectives coincided with those of health-care providers. Practical and time constraints limited our ability to recruit caregivers; however, we believe that reflection of their views is important, even if only as a preliminary and limited indication of this perspective.

Focus group interviews were approximately one hour each; individual interviews lasted approximately 30 minutes. Prior to the interview, participants were shown a demonstration video about Tyze (<http://www.youtube.com/watch?v=UQcXYjtJFRo&noredirect=1>) highlighting key features. Those who participated in the phone interview were given study information and a link to the video ahead of the scheduled call. All interviews followed a semi-structured interview guide⁽⁴⁰⁾ (Appendix 1).

Data Analysis

Interviews were audio-recorded, transcribed verbatim and uploaded into NVIVO8 for analysis. Data analysis took place in four steps: 1) descriptive coding, where codes described the study sample; 2) topic coding, where codes reflected the topic being discussed during focus group interviews; 3) analytic coding, where in-depth connections were made within the data; and finally 4) theming, where the major themes from the data were identified.⁽⁴¹⁾ Data from all participant groups were combined.

Peer debriefing sessions with co-authors were conducted to discuss methods and analysis of data, the rationale for methods decisions, different codes, and how best to reflect themes emerging from the analysis. Voluntary member checking occurred with caregiver and service provider participants, which resulted in refinement of themes. The first author kept an audit trail throughout the study process.⁽⁴²⁾

This study received ethics clearance from the University of Waterloo's Office of Research Ethics (ORE # 17694).

RESULTS

Characteristics of study participants are presented in Table 1 (28/31 focus group participants completed a questionnaire on their demographic characteristics).

The topics that emerged from the initial data analysis were privacy concerns, existing communication challenges, and opportunities for teamwork. These were further refined using analytic coding and theming. As a result, two major themes were identified as critical to understanding the potential for the use of networks in a home-care setting: 1) improved family engagement and communication, and 2) setting boundaries to minimize barriers.

Improved Family Engagement and Communication

Participants[†] described communicating methods as face-to-face, telephoning, writing notes or emailing, and challenges with each mode of communication were identified.

Face-to-face and phone communication are often difficult with conflicting schedules. Additionally, service providers often use personal cellphones for work and were hesitant to share this number with clients. Service providers and caregivers often leave each other notes in the client's home. Participants commented that notes are easily misplaced, misunderstood or discarded, with no guarantee or confirmation the note will be read. Participants felt positively about email; however, some providers indicated this was considered a confidentiality breach. Overall, participants expressed the opportunity for improvement to communication methods. Online networks would not solve all communication problems, but may help to support communication needs in some instances.

Participants expressed that networks may improve communication, information exchange, and engagement between service providers and caregivers, including those caring from a distance. They felt networks would be especially appropriate for caregivers of chronically ill or clinically complex clients, especially those with dementia, who are palliative, or who have a developmental disability. They perceived networks as useful in scheduling home visits, allowing for awareness of services being provided, and for sharing information in a single place.

Participants suggested networks could be helpful to share strategies for caring for a specific client by posting what approaches were most successful. Other uses include

TABLE 1.
Participant demographics

<i>Question</i>	<i>Response</i>	<i>Percentage of Participants Who Responded</i>
SERVICE PROVIDERS		
	N(28)	%
<i>Gender</i>		
Female	28	100
<i>Age</i>		
19-24	2	7.1
25-34	5	17.9
35-44	3	10.7
45-54	13	46.4
55-64	5	17.9
<i>Level of Education Completed</i>		
Some college	1	3.6
Completed college	7	25.0
Some university	2	7.1
Completed university	9	32.1
Some post-graduate	1	3.6
Completed post-graduate	8	28.6
<i>Years in current role</i>		
<1	3	10.7
1-5	12	42.9
6-10	5	17.9
>10	8	28.5
FAMILY CAREGIVERS		
	N(4)	%
<i>Gender</i>		
Female	3	75
Male	1	25
<i>Age</i>		
55-64	2	50
65-74	1	25
74-84	1	25
<i>Level of Education Completed</i>		
High school	1	25
Completed college	1	25
Completed university	1	25
Completed post-graduate	1	25
<i>Years as a Caregiver</i>		
<1	1	25
1-5	2	50
>10	1	25

sharing client information such as equipment needs, health status updates, medication changes, and community resources. Networks also allow caregivers to clarify information for which they feel unsure.

Participants reported that the use of networks has the potential to further encourage families to participate actively in care conversations by creating a more supportive and interactive care environment that would allow for a direct way of accessing patient information and connecting to their circle-of-care. Caregivers also noted potential benefits of connecting with service provider in a network:

“Someone who really needs that social contact, the emotional back-up. Ideas about how to care for their person...I think the contact with other people and the sharing of ideas and letting you know that you are not alone in this and there are people out there that you can reach out to.” (Caregiver)

Networks create an environment where all client information could be stored in a single location. Participants perceived this as useful because as information is added to the network, a client history is created.

“I think it would help me do a more thorough job if we were able to understand the client and their history... You don’t get any information on the referral and you get what you get from the client so that could help me get a better picture of the clients.” (Service provider)

Service providers felt this history could also be used to help a client who may be required to transition into long-term care or to another community-based setting.

Participants discussed concrete benefits which included time-, cost-, and work-savings, as well as offering users greater convenience and efficiency in providing care. However, participants from both groups felt convenience alone is not enough for the adoption of a new technology.

Setting Boundaries to Minimize Barriers

Participants wanted the boundaries of use for online services to be clearly defined, such as who covers costs, who owns the network, who is involved, expected time commitment and duration of network use.

Service providers were concerned financial costs of the network would be a barrier to use for low-income families and agreed agencies should offer networks as part of the service they provide until the agency relationship ends. In addition to these logistical concerns, there were concerns with the technology’s security, and the potential to reduce (as opposed to supplement) face-to-face interactions.

Discomfort with the technological aspects of networks, mandated boundaries, and perceptions that involvement in

the network would create more work were barriers cited. Participants from both groups expressed discomfort with communicating through technology, including trust issues with this method of communication. Concern that computer-mediated communication has the potential to replace in-person interactions and to create misinterpretations was expressed. Service providers were also concerned about the accuracy and clarity of information from caregivers and clients because of the lack of face-to-face communication cues.

Due to the sensitive nature of information potentially being posted by service providers on the network, participants wanted to ensure the users’ privacy and confidentiality are upheld. As such, service providers would first need to receive additional approvals for use. Participants also expressed concern that their regulating professional colleges may place restrictions on the methods of communication, such as email, used by providers with clients and families.

Participants stated they would find it helpful to be able to pilot the online network before committing to its use. While the potential for use of networks in home care was recognized, participants felt it would likely take time before their use catches on.

“It has to grow organically. Like, that’s the thing with Facebook, with Twitter, with all of the things that are out there now... It just happened to be the right place, the right thing at the right time.” (Service provider)

Participants suggested this could be accelerated by giving potential users the opportunity to try out the service prior to committing to its use.

DISCUSSION

Service providers could envision multiple uses and benefits for online personal networks in home care. While the main focus of this study was to gain the perspective of service providers on connecting with the networks used by caregivers, our limited exploration with caregivers suggests they see similar benefits.

Several issues need to be addressed to ensure optimal implementation, adoption, and use of networks. The *Diffusion of Innovations* theory provides a lens through which to explore several of the opportunities and challenges highlighted by participants. An important piece in this theory is the perceived usefulness and relative advantage of the service in respect to existing alternatives.⁽³⁶⁾ Potential users need the benefits of using a technology to be visible,⁽³⁶⁾ and participants indicated that there is an opportunity for communication and information-sharing to be enhanced, but not replaced, by networks.

Before service providers become involved in networks, they must better understand how the service is compatible with their current workflow and service/job expectations.

(36) Participants were clear about the importance of ensuring parameters of use are clear to end-users.

Concerns discussed around network ownership and associated security are not unique to technology in home care;

TABLE 2.
Additional quotes from study participants

Improved Family Engagement and Communication

“They’re not allowed [to email us]. Then there are phone calls, and good luck on catching me. When they’re working, I’m working.” (Caregiver)

“It’s like, I have someone, a palliative client, who’s got tons of people coming in all the time, and the wife suffers from a lot of on the edge burnout because, it’s just coming and going all the time, and she feels like she needs to sort of keep things organized, but this would really help put the onus on a lot of other people.” (Service Provider)

“And for that reason it lends itself to accountability like everybody on that network who is providing care is accountable to the other members of the network, so it’s more cooperative, let’s say, or collaborative. (Service Provider)

“And I could also see if you had the type of client who was tech savvy, liked to feel that they were self-directing everything, I think they would enjoy this.” (Service Provider)

“If you’re doing something on your own, it’s a big job and you’ll definitely need help, and for those types of people they would be using your [online network] left right and centre, wanting more and more help and guidance.” (Caregiver)

“You know, things like diagnosis, let’s say it’s a diabetic person, so we put you, you know, information of diabetes and what to look for and so the family would see that” (Service Provider)

“So for a home to a long-term care facility.....Can you imagine someone’s at home, they’re on that network, so all of this...[information] they’re putting into it, and then they go into a long-term care facility and the family says ‘we’re on this network, we’re giving you permission to go in and take a look at all the stuff that Mom’s been doing.’ Without having to sit down and gather information.” (Service Provider)

I could see that it could have some potential benefit for them feeling very much like there is a team. You work hard for them and it’s not just like when we come in and the left hand doesn’t know what the right hand is doing, we pretend we are a team but we’re not, you know - well, we work in relative isolation. So for the client, they can really feel that there is a team working on it. (Service provider)

“It kind of acts as a double insurance. Even though you might call the family, maybe they [forgot what] you said to them on the phone, they could always then go back later and look it up”. (Service provider)

Setting Boundaries to Minimize Barriers

“I guess I would just be concerned about the kind of information that is shared depending on what you are there to provide the clients. Someone that is driving the client would want to share some information, but if the therapist is going in they might want to share, you know, other types of information that might not be appropriate for the driver to have of the clients.” (Service Provider)

“How long should [information] stay up there, I mean for example with Facebook, everything is up there since you opened your network or your account so should this have a finite amount of time that something is up there?” (Service Provider)

“It has to be convenient and it has to be easy, no question about that. You don’t want it difficult or else [users] will simply give up. The more simple and the easier you can make it, the more use it would be to anybody.” (Family Caregiver)

“It kind of reminds me of how our email works. Only certain people can access it if you have the access to it. So I kind of think that all that information could be from the vault and then the people privy to that information could go into there because somehow I understand that it’s very very secured because we just had examples of peoples’ wills on here, medication lists, financials, medical history. That’s the stuff they wouldn’t just put out anywhere and it’d have to be new so it would have to have some time of security for that. So I think if it had that, it’d be great.” (Service Provider)

“Because we have to be very clear that we would be involved in a professional clinical nature. It’s not Facebook. We’re not friends with them. After a discharge I don’t – don’t send me updates about where you’re going and what you’re doing. It’s a professional involvement.” (Service Provider)

the ability to store health information in multiple locations creates opportunity for inappropriate information storage, access, and use, and diffuses the responsibility of protecting health information across the entire care network.^(43,44) These concerns can be addressed by creating clear guidelines about how patient information may be used when it is accessible electronically.⁽⁴³⁾ These types of concerns were expressed primarily from service providers.

A disadvantage of online communication is the potential for nonverbal cues to be lost; however, this form of communication also presents opportunities: online communication provides quieter members of a group an opportunity to become more active contributors and, therefore, have a more engaged role in caregiving.^(45,46)

Service providers and caregivers were concerned that becoming involved in a network would be time-consuming as opposed to efficient due to skill-level with computers. This barrier is frequently cited in the health-care context.^(47,48) This speaks to “relative advantage”:⁽³⁶⁾ efficiencies and incentives may need to become visible over a longer term, prior to widespread adoption of this innovation in home care. For example, for caregivers, training and comfort using networks may be necessary, while for service providers, incentives may range from perceived improvements in workflow and in cost and time-savings, coupled with convenience and ease-of-use. These findings echo similar results from studies investigating drivers of health information technology uptake.⁽⁴⁸⁻⁵⁰⁾ Additional benefits relate to the ability to provide better care and an opportunity for greater social support.⁽¹⁴⁾

The importance of social support for caregiver well-being is considerable,^(14,21,30,51,52) and networks may allow members to provide/receive support when face-to-face or when telephone conversations are not possible. The addition of service providers to networks adds a valued dimension of social support allowing caregivers to feel empowered as they provide care.⁽⁵³⁾

Participants felt networks could help bridge continuity gaps, including following a consistent care plan, relationship-building with and between providers, and having information available and complete.^(54,55) The network was also viewed as beneficial in its potential to store communication history, share information on the client/caregiver needs, and update network members on the client’s health status. Moreover, in a recent expert roundtable about technology and caregiving, participants identified better online connectivity between family caregivers and health professionals as one of the most important future directions.⁽²⁶⁾

Limitations

The major limitations of the study were the small number of caregivers available to participate, limited male participants (one male participant), sample heterogeneity, and computer literacy as a requirement for participants. Future research should aim to include more caregivers, including more males, which would also allow for a robust comparison of the perspectives

of care providers versus family caregivers. Practical and time constraints limited our ability to interview caregivers; however, we believe that reflection of their views is important, even if only as a preliminary and limited indication of this perspective.

CONCLUSIONS

This study adds to existing literature by outlining potential next steps for implementing a network between service providers and caregivers. Concerns around privacy, confidentiality, information ownership and parameters of use, and funding must be addressed at a policy, professional, agency, and staff level. A formal approval process may help facilitate feelings of safety around network use.

Caregivers and service providers could use our results to anticipate and work through barriers identified by staff when implementing an intervention using networks or other online methods to communicate. The perceived merits of a network could be used to help pinpoint when and how the network could be used. Our findings suggest this type of intervention might not be appropriate for all clients, but may help supplement existing relationships.

Although our findings support the potential for a network to enhance home-care support, more research is needed to test the actual use of networks to facilitate and coordinate care between service providers and caregivers.

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CONFLICT OF INTEREST DISCLOSURES

At the time of data collection, Dr. Byrne was affiliated with Tyze, which was used as an example of an online personal network for study purposes. This potential conflict was indicated to participants during data collection, and Dr. Byrne was not present during data collection; however, Dr. Byrne helped guide the study design and provided revisions to this manuscript. Dr. Byrne is no longer affiliated with Tyze and has not benefitted financially or in other respects from her role in this study. Tyze did not provide any financial support for the study. The authors declare that no other conflicts of interest exist.

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APPENDICES

Appendix 1. Sample interview questions

Feedback based on participant engagement session

What was your overall impression of the online demonstration? Is there anything you think could be improved about the session?

What are some ways that you think people are using Tyze?

Overall impressions of Tyze for use in care

Overall, what are your general impressions of the Tyze networking tool?

Tyze during transitions

Overall, can you see Tyze playing a role in achieving smoother transitions from hospital to home/ home care? Why or why not? Do you see Tyze as a potential solution to issues with continuity of care for clients? Why or why not?

Implementation at [agency]

What barriers or roadblocks do you think exist for using Tyze with clients and families?

How do you think the use of this sort of networking tool would impact the services you provide to clients and/or their families at [agency]?

Use of technology in a health context

What types of technologies do you currently use to communicate with others in your day to day role at [agency]?

Is there a technology that you wish you could use with clients and families? Why?

How do you think technology could be better used in our healthcare system? With home care?

*For this paper, “networks” will be used to indicate online networks unless otherwise indicated.

†Participants refers to the collective group of caregivers, service providers (case managers and direct providers), unless otherwise indicated.