Usability of a care coordination application to ease family caregiver burden: A dementia case study

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Background In Canada, an unprecedented number of friends and family are caregivers. Caregiving is known to impact psychological well-being, especially when a loved one has dementia, although good family functioning and high self-efficacy are associated with increased resiliency. Emerging care coordination technologies aim to ease the burden of care; however, little is known about their effectiveness. This case study aims to evaluate the usability of a care coordination application (app) and its effectiveness at easing caregiver burden. **Methods** Data from 2 dyads (primary and secondary caregivers) were analyzed from a total 4 family participants who were recruited from a Toronto-based memory clinic to use the app, Zalio™ to coordinate care for a loved one with Alzheimer's disease for 6 weeks. Zalio's developer trained participants prior to practice and active use phases. System Usability Scale (SUS) assessed perceived usability every 2 weeks. The Revised Scale for Caregiving Self-Efficacy, Short version of the Zarit Burden Interview (ZBI), and General Functioning (GF) subscale of the McMaster Family Assessment Device (FAD) measured caregiving self-efficacy, caregiver burden, and perceived family functioning, at baseline and week 6. **Results** All participants rated Zalio™ a usable and above average app (SUS > 68). No consistent improvement was seen in self-efficacy. Caregiver burden scores decreased on short version of ZBI in secondary caregivers. GF scores on subscale of FAD decreased in primary caregivers and one secondary caregiver. **Implications** Our research is a first step towards understanding the usability of a care coordination app. Further studies with larger samples are required to determine its effectiveness at easing caregiver burden.

Keywords: case study, dementia, family caregiving, caregiver burden, applications, care coordination, Zalio™

INTRODUCTION

Family caregiving

Canada's population is aging and the implications for family caregiving are immense. Statistics Canada predicts that seniors will represent approximately 25% of the total population by 2036[1] and a Population Health Expert Panel convened by the Alzheimer Society of Canada predicts there will be an estimated 937,000 Canadians over age 65 living with dementia by 2031[2]. Consequently, the burden of care is being assumed by an unprecedented number of family caregivers, who are friends and family attending to the needs of loved ones at home for no pay[3].

Caregiver burden is "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience"[4]. Psychological consequences of caring, including stress, depression, and decreased sense of subjective well-being[5] may be somewhat buffered by positive feelings and a high sense of belief in one's capability to provide care (self-efficacy)[6-8]; however, caring for a person with Alzheimer's disease or other dementias is especially challenging with poorer caregiver outcomes[9]. Higher perceived effective communication amongst family members and the ability to differentiate roles and functions have also been associated with lower perceived burden, leading researchers to recommend that family functioning be an included outcome measure in caregiver intervention studies[10,11]. However, research has tended to focus on primary caregivers (PCGs) who provide the majority of care and have high levels of burden[12] and not secondary caregivers (SCGs) who assist with supplementary care tasks such as grocery shopping, service coordination, and transportation services[13] and are generally thought to have lower levels of burden[12].

Technology and caregiver burden

Technology's ability to ease caregiver burden, including information and communication technologies (ICT), seems promising. Numerous mainly psychoeducational internet-based technology interventions have been studied with at least 5 systematic reviews[14-18] and 1 literature review[19] having demonstrated positive psychological outcomes, including ease of depression and increased caregiving self-efficacy. However, the overall clinical effectiveness of these interventions is unclear due to large variation in approaches and lack of standard outcome measures and control[14-18]. Other assistive technologies have been studied that aim to improve a person with dementia's functional independence or give caregivers peace of mind (e.g., smart homes and remote monitoring systems)[20]. However, a very recent literature review confirms the lack of technologies developed specifically for dementia caregivers[21]. Furthermore, much of the literature predates the advent of mobile and web-based applications (apps). However, despite advanced technology, experts concede that it is still only modestly contributing to supporting family caregivers due to a lack of good burden measures to assess the effectiveness of smart technologies[22] and the failure of many technologies to have solved the daily problems that people face[23].

Addressing care networks

In addition to helping care tasks, experts argue that for caregiver technology to be meaningful it must help coordinate the networks and relationships associated with caring and not be aimed at a simple dyad relationship[22]. Prior deployment of the CareNet Display[24], revealed that both primary network members and those on the periphery desire care coordination tools and benefitted from a system to communicate, connect, and share tasks loads. However, despite the desire for care coordination tools, few technologies to date have been aimed at helping friends and families coordinate care within a care network[25]. More recently; however, care coordination prototypes are emerging, including a smartphone technology that aims to spread the caregiving load by directing requests to the network member who is closest to the care recipient at the time of a request[26]. A pilot study also suggests that online platforms designed to strengthen cooperation and communication between dementia caregivers are useful[27]. However, the online platform failed in a larger feasibility study as a result of a lack of personal guidance (personal communication, R.Verway, February 7, 2017). Therefore, it is essential to have technology studies to ensure real world application.

Usability studies

According to the International Organization for Standardization (ISO) 9241-11[30], usability is "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use." Usability studies have been recommended in technology development to ensure a technology reflects user needs and requirements[28,29]. With a small sample size of approximately five subjects, eighty percent of usability problems are usually detected[31]. User satisfaction is particularly quick and easy to measure[32]. It is important to assess user satisfaction as technology has been found to be most frequently adopted when it has high perceived usefulness and is viewed as being easy to use[33]. One of the only known studies to test the usability of commercially available care coordination mobile apps with diverse populations, including low income caregivers, concluded that all of the apps were of "suboptimal usability" due to retrieval problems, frustrations with multiple screens, a lack of clarity of functions, and low user confidence[34]. The importance of usability studies is also highlighted by a study[35] that reported that Alzheimer's disease caregivers did not adopt a web-based and android app, (CareHeroes), that was designed to support and enhance communication as they were too overwhelmed, not technologically proficient, and unable to incorporate it into their routine[35].

Research purpose

Care coordination web-based apps designed for family caregiving are starting to emerge on the market. Some of these apps include, CareZone, CaringBridge, Lotsa Helping Hands, and Caring Village. These apps aim to help caregivers coordinate care within a network and promote easing the burden of care. However, to date no known literature has been found to assess the effectiveness of these apps at decreasing caregiver burden. We are conducting this research to address this gap in the literature and seek to answer our research question - what is the perceived usability of a web-based care coordination application and its effectiveness at easing the burden of caregiving? We anticipate that through individual case studies, we can determine whether dementia caregivers perceive a care coordination app to be a usable app. We aim to preliminarily explore the effectiveness of the app at decreasing caregiver burden and anticipate that its effectiveness may differ for PCGs and SCGs; however, we recognize the limitations for a significant change in burden within a 6-week usability study.

Objectives

Our research question aims to address 3 primary objectives: (1) whether PCGs and SCGs perceive a web-based care coordination application to be a useful tool; (2) whether there is an improvement in perceived self-efficacy in caregiving in PCGs using a web-based care coordination tool; and (3) whether there is a reduction in caregiver burden in PCGs using a web-based care coordination application. Our question also seeks to explore 2 secondary objectives: (1) whether there is a reduction in caregiver burden or improvement in caregiving self-efficacy in SCGs, and (2) whether there is an effect on perceived family functioning in PCGs and SCGs using a care coordination tool.

METHODS

Study design

Case study design was used to develop a preliminary clinical knowledge base on the usability of a care coordination app as an approach to helping families coordinate care for a loved one with dementia. Case study allowed for a more thorough interpretation of outcome measure results through an in depth exploration and description of individual families (Care Circles) to understand factors that may have influenced user satisfaction, such as differences in primary and secondary family participant characteristics, care-recipient (CR) characteristics, and extraneous variables like family dynamics[36]. As family care coordination apps are relatively new and little is known about their effectiveness, case study design was chosen to practically disseminate information to professional colleagues on innovative approaches in dementia patient care[36]. The study was approved by the Research Ethics Board of the University of Toronto.

Care coordination application

The family care coordination app under investigation is Zalio™. We chose to evaluate Zalio™ as it was recommended to Toronto Memory Program as a helpful tool for dementia caregivers. It was important that Toronto Memory Program understand the usability of Zalio™ in order to better guide caregivers with practical solutions. Zalio™ was also chosen because the developer was Toronto-based, enabling participants to have direct training and support during the study. Zalio™ is a private and secure web-based app for family members (or members of a Care Circle) to share information, coordinate care activities, and stay connected. Zalio™ is accessible from any device with an internet-enabled browser and is available through participating organizations that offer it as a benefit to customers or consumers. There are 3 main features: (1) Activity Coordination allows family members to coordinate activities on a shared calendar, such as appointments. Family members can request assistance with activities from other members in the Care Circle; (2) Care Wall allows family members to post and share important information and observations about a care-recipient to help members stay connected; and (3) Vital Information enables family members to keep up to date information on a care-recipient, such as medication, names of doctors, and other vital contact information. Zalio™ can be synchronized with a care member's personal calendar and sends out notifications of updated information.

Participants

Participants were recruited from a memory clinic located in mid Toronto with a large clientele of patients with dementia, and caregivers. A study advertisement was posted in the clinic waiting room along with literature on Zalio™. Clinic staff directed interested participants to the researcher who provided study detail either in person or over the telephone. The baseline visit occurred after the potential participants consented to participate in the study. Participants who completed all study visits were provided with a $50 gift card of their choosing.

Inclusion criteria consisted of individuals who were at least 19 years of age, fluent in English, competent to consent, and who were providing some aspect of care coordination (e.g., arranging appointments, tracking medication) to a person with dementia. Participants were eligible to participate if they were coordinating care with at least 1 other family member or friend for the same care-recipient within a Care Circle. Each Care Circle consisted of 1 PCG and at least 1 SCG. A PCG was defined as a person providing the most time coordinating care within a Care Circle or the person who self-identified as the primary

Table 1. Care Recipient (CR) characteristics for family 1 and family 2

	Family 1	**Family 2**
Characteristic	**CR1**	**CR2**
Age	78	63
Gender	Male	Male
Diagnosis	Alzheimer's disease	Alzheimer's disease
Frequency that dementia professional supports/organizations accessed per week	Never	2-3 times/week

Table 2. Family Participant Characteristics for Family 1 and Family 2. (PCG = Primary Caregiver; SCG = Secondary Caregiver)

	Family 1		**Family 2**	
Characteristic	**PCG1**	**SCG1**	**PCG2**	**SCG2**
Age	73	48	56	32
Sex	Female	Female	Female	Female
Marital status	Married	Married	Married	Married
Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian
Education	University	University	College	College
Employment status	Retired	Full-time	Unemployed	Stay at home mother
Relation to CR	Spouse	Daughter	Spouse	Daughter
Distance to CR (by car)	Same household	10-30 min	Same household	< 10 min
Years caregiving	3-4	3-4	3-4	1-2
Access of caregiver supports (per month)	Never	Never	Never	Never
Caregiving frequency	Daily	2-3 times/mth	6-7 times/wk	6-7 times/wk
Care tasks	Cooking, scheduling, general reminders, banking, medication	General reminders	Cooking, driving, shopping, scheduling, general reminders, housekeeping	Cooking, driving, shopping, scheduling, general reminders
Communication methods with other care circle member	Telephone, email, text, in person	Telephone, email, text, in person	Telephone, email, text, in person	Telephone, email, text, in person

caregiver. A SCG was defined as a person who is not providing the majority of care coordination within a Care Circle or who self-identified as a person who is supporting a PCG. Participants had to have access to a computer, iPad or smartphone and be comfortable with technology. They could not have had prior exposure to Zalio^{TM} or other care coordination technologies and could not be currently enrolled in a stress management program. Participants were excluded if they were paid or professional caregivers, had evidence of cognitive impairment, or were a sole caregiver who was not coordinating care with a secondary caregiver. Participants were also excluded if providing care to a care-recipient who was residing in a long-term care.

Outcome measures

The System Usability Scale (SUS)[37] was used as a primary outcome measure to assess the perceived usability (learnability and satisfaction)[38] of Zalio^{TM}. It is a well-validated, 10-item self-administered tool that is the industry standard for differentiating usable from unusable systems. Items are ranked on a 5-point Likert scale from Strongly Disagree to Strongly Agree. A SUS score ≥ 68 is considered above average and data can be normalized to a percentile ranking for product comparison[32]. Scores can be associated with an adjective rating (e.g., poor, good, excellent) and letter grade score (e.g., A, B, C)[39]. Scores in the 80s are considered good, equal to a B grade, scores in the 90s are considered excellent, equivalent to an A grade, and a score of 100 represents the best imaginable app[39].

The Revised Scale for Caregiving Self-Efficacy[40] was used as a primary outcome measure of self-efficacy in PCGs and a secondary outcome measure of self-efficacy in SCGs. This is a 15-item clinician administered questionnaire assessing perceived caregiving self-efficacy in 3 domains. The 3 subscales (Obtaining Respite, Responding to Disruptive Patient Behaviours, and Controlling Upsetting Thoughts) have a strong internal consistency and adequate test-retest reliability. Construct validity is supported by relationships between these three facets of perceived caregiving self-efficacy, and depression, anxiety, anger, and perceived social support. Yet validation for administration over the phone is unknown[40].

The Short Version of the Zarit Burden Interview (ZBI)[41] was used as a primary outcome measure to assess the effectiveness of Zalio^{TM} to ease caregiver burden in PCGs and a secondary outcome measure of caregiver burden in SCGs. It is a 12-item self-administered scale that measures burden in dementia caregiving and strongly correlates to the initial well-validated 22-item version of the Zarit Burden Interview (ZBI)[42]. A score ≥ 17 indicates high burden[41].

The General Functioning (GF) subscale of the McMaster Family Assessment Device (FAD)[43] was used as a secondary outcome measure to assess the effectiveness of Zalio^{TM} at impacting perceived family functioning. It is a 12-item self-administered scale with good reliability and validity that assesses global family functioning, and distinguishes between healthy and unhealthy families. A score ≥2 indicates problematic family functioning and the higher the score, the more problematic the family member perceives the family's overall functioning to be[43].

Statistics

Descriptive statistics were used to explore and describe family participants. The score difference between baseline and the end of study (week 6) was assessed for The Revised Scale for Caregiving Self-Efficacy, the short version of the ZBI, and the GF subscale of the FAD. Data from the SUS were converted to a score out of 100 to determine the usability of Zalio™. In each case, differences between primary caregiver and secondary caregiver (s) were also explored.

Procedure

The study took place over approximately 6 weeks and consisted of 3 phases: Baseline, Training, and Active Use.

Baseline phase

After participants provided consent to participate in the study, the researcher contacted them to complete the demographic questionnaire (*Tables 1* and *2*), the Revised Scale for Caregiving Self–Efficacy, the short version of the ZBI, and the GF subscale of the FAD. After both PCG and SCG in a Care Circle had completed the questionnaires, the developer of Zalio™ contacted each of them to arrange the training visit.

Training phase

The developer of Zalio™ carried out an approximately 1-hour training visit via telephone with the PCG and SCG(s), either individually or as a group. The purpose of the training visit was to demonstrate features of Zalio™. Participants could access Zalio™ from either a personal computer or a smart phone. Participants were instructed to use Zalio™, to help coordinate care at least 3 times a week, or as much as possible, for 2 weeks. Participants were encouraged to contact either the developer or the researcher directly with any questions. Participants had access to an online training video to review the training session material whenever necessary throughout the study. At the end of the 2-week training phase, the researcher contacted each PCG and SCG to complete the SUS for the post-training visit.

Active use phase

Participants were asked to continue using Zalio™ at least 3 times a week, or as much as possible, for 4 weeks. Participants were encouraged to contact the researcher with any questions regarding the use of Zalio™ during this phase. After 2 weeks of actively using Zalio™, the researcher contacted both PCG and SCG to complete the SUS for the 2-week follow-up visit. Participants were then asked to continue using Zalio™ for the remaining 2 weeks of the study. At the end of 4 weeks of actively using Zalio™, both PCG and SCG were asked to complete the SUS, The Revised Scale for Caregiving Self–Efficacy, the Short Version of ZBI, and the GF subscale of the FAD. Participants were also encouraged to give general feedback on Zalio™ to the researcher or to the developer at the end of the study.

All questionnaires were completed online with the exception of The Revised Scale for Caregiving Self–Efficacy, which was administered by telephone. Participants were asked to complete questionnaires within 5 days of being notified.

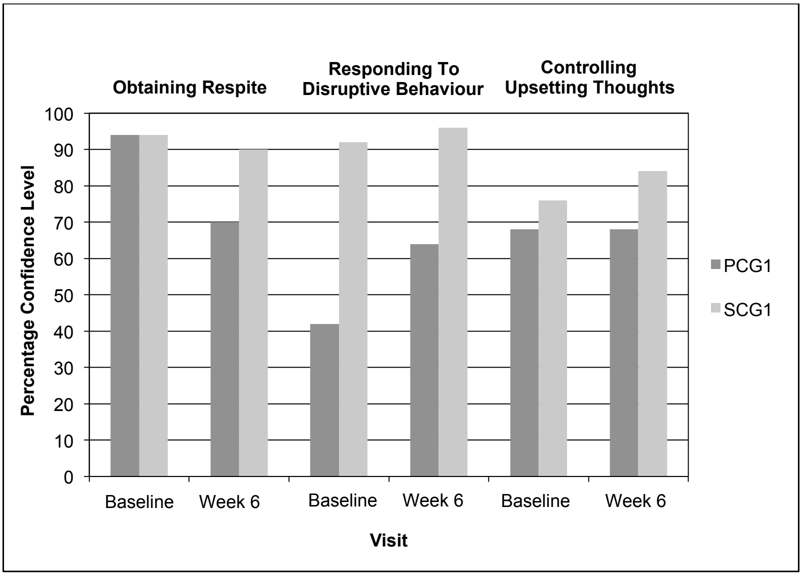

Figure 1. Percentage confidence level in caregiving domains on the revised scale for caregiving self-efficacy[40] in Family 1.

RESULTS

A total of 13 family participants were recruited for the study; however, for the purpose of this paper and our timeline, only data from 4 of those participants were useable. We plan to publish on the remaining data as part of a future manuscript.

The 4 family participants were from two (2) families (2 Care Circles), Each Care

Circle consisted of 1 PCG and 1 SCG. *Tables 1* and *2* provide an overview of characteristics of care-recipient and family participants of both families 1 and 2.

Cases

Data and results will be presented by family case studies to understand the perceived usefulness of Zalio™ at coordinating care within a Care Circle. Within each case, data were described by outcome measure and caregiver type to explore differences between PCGs and SCGs in their perceived usability of Zalio™, level of caregiving self-efficacy, level of caregiver burden, and perceived level of family functioning, as well as change in outcome measures within the study.

Family 1

Usability of Zalio

Both family participants rated Zalio™ a usable app (SUS ≥ 68) at all visits and scores remained constant during the training and active use phase. PCG1 scored Zalio™ consistently at 97.5, indicating that she perceived it to be an excellent app equivalent to an A grade ranking[39]. SCG1 rated Zalio™ consistently at 100, revealing that she perceived it to be the best imaginable app[39].

General feedback on Zalio

PCG1 reported using Zalio™ approximately 5 times a week. SCG1 reported using Zalio™ approximately 4 to 5 times a week. Both family participants reported that they planned to continue using Zalio™. PCG1 particularly liked that she could access CR1's medication list from any smartphone. SCG1 stated that Zalio™ was easy to use and believed that anyone could use it. She reported that it was an excellent tool to communicate with PCG1 regarding CR1's doctor's appointments and medication issues. SCG1 also suggested that Zalio™ could help families who were coordinating childcare.

Caregiving self-efficacy

Figure 1 shows PCG1 and SCG1's percentage confidence level in 3 caregiving domains (Obtaining Respite, Responding to Difficult Behaviour, Controlling Upsetting Thoughts) on The Revised Scale for Caregiving Self-Efficacy[40] at baseline and week 6.

PCG1 had a lower percentage confidence level than SCG1 in all 3 caregiving domains at baseline and week 6 excluding baseline confidence in obtaining respite that was equivalent to SCG1. Confidence level in obtaining respite decreased for both participants at week 6; PCG1's level decreased from 94% to 70% and SCG1's confidence level decreased from 94% to 90%. Confidence level in responding to difficult behaviour increased for both participants; PCG1 increased from 42% to 64% and SCG1 increased from a level of 92% to 96%. At week 6, PCG1's confidence level in controlling upsetting thoughts remained stable at 68% and SCG1's confidence level increased from 76% to 84%.

Caregiver burden

Figure 2 displays the self-reported level of caregiver burden on the short Version of the ZBI[41] in PCG1 and SCG1 at baseline and week 6.

PCG1 had a high level of caregiver burden at baseline and week 6; whereas, SCG1 had levels below the cut off for high burden at both visits. At week 6, PCG1's baseline burden score of 24 increased to 26 while SCG1's baseline burden score of 10 decreased to 5.

Perceived family functioning

Figure 3 depicts PCG1 and SCG1's perceived level of family functioning on the GF subscale of the FAD[43] at baseline and week 6.

At baseline and week 6, PCG1 perceived her overall level of family functioning to be problematic while SCG1 did not perceive her family functioning to be problematic at either visit. At week 6, both participants showed a decline in perceived level of problematic functioning; PCG1's score decreased from 3 to 2.42 and SCG1's

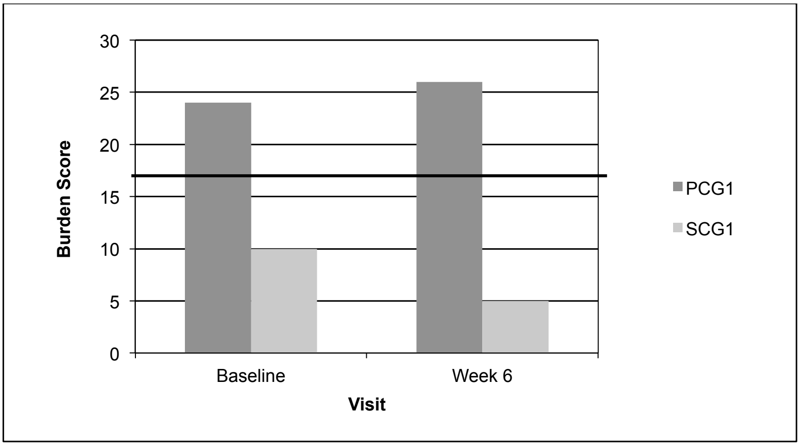

Figure 2. Level of self-reported caregiver burden on the short version of the Zarit Burden Interview (ZBI)[41] in Family 1. Line on figure above indicates a high burden level at n ≥ 17[41].

score decreased from 1.92 to 1.25.

Family 2

Usability of Zalio

Both PCG2 and SCG2 perceived Zalio™ to be a usable app (SUS ≥ 68) at all 3 visits. At the post-training visit, Zalio™ had a SUS score of 87.5 from PCG1 and a score of 80 from SCG2, equivalent to grade B ratings[39]. At the 2-week follow up visit, Zalio™ had equivalent SUS grade A scores of 90, and at the 4-week follow up visit, PCG2's score decreased back to 87.5 while SCG2's score remained at 90. Scores during the active use phase indicated that both PCG2 and SCG2 perceived Zalio™ to be an excellent app[39].

General feedback on Zalio

PCG2 reported using Zalio™ approximately twice a week and SCG2 reported using Zalio™ approximately 3 times per week. At the end of the study, PCG2 and SCG2 reported that they would like to continue using Zalio™. PCG2 reported that Zalio™ was helpful for arranging physiotherapy, massage, and occupational therapy appointments for her husband (CR2) who was, unfortunately, involved in a car accident during the study. However, PCG2 was sometimes hesitant to use Zalio™ because she feared that her husband who shared her computer and email address might see what she was posting on Zalio™. She subsequently set up a separate email for Zalio™ that helped alleviate this fear. PCG2 could not receive Zalio™ updates on her smartphone as it was not linked to an external calendar, such as Google Calendar. She suggested that Zalio™ have its own internal calendar. SCG2 reported that Zalio™ was very helpful to communicate information to PCG2 without having to speak to her directly.

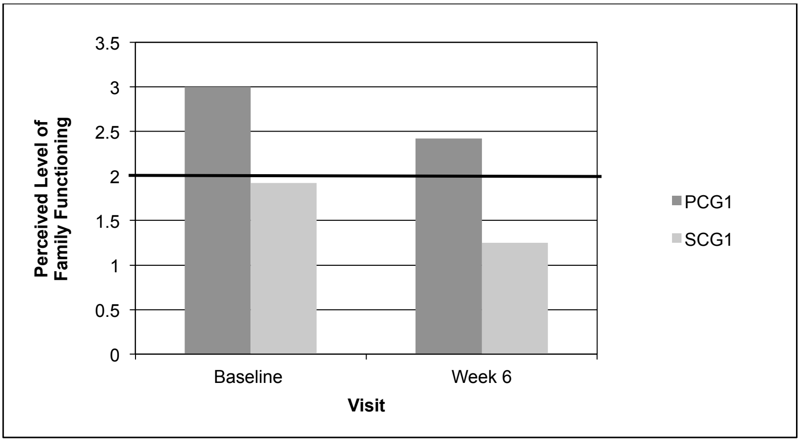

Figure 3. Perceived level of family functioning on the General Functioning (GF) subscale of the McMaster Family Assessment Device (FAD)[43] in Family 1. Line on figure above indicates level of perceived problematic family functioning (n ≥ 2)[43].

Caregiving self-efficacy

Figure 4 shows PCG2 and SCG2's percentage confidence level in 3 caregiving domains (Obtaining Respite, Responding to Difficult Behaviour, Controlling Upsetting Thoughts) on The Revised Scale for Caregiving Self-Efficacy[40] at baseline and week 6.

PCG2 had lower percentage confidence levels than SCG2 in all 3 caregiving domains at baseline and week 6. At week 6, PCG1's confidence level in obtaining respite increased from 52% to 54% and her confidence level in controlling upsetting thoughts increased from 64% to 72%; whereas, SCG2's confidence in obtaining respite declined from 86% to 72% and her confidence in controlling upsetting thoughts declined from 96% to 94%. Level of confidence in responding to disruptive behaviours decreased for both participants, from 76% to 74% for PCG2 and from 92% to 88% for SCG2.

Caregiver burden

Figure 5 displays the self-reported level of caregiver burden on the short Version of the ZBI[41] for PCG2 and SCG2 at baseline and week 6.

PCG2 had a higher level of caregiver burden than SCG2 at baseline and week 6. At week 6, PCG2's baseline high burden score of 28 increased to 29; whereas, SCG2's baseline high burden score of 19 decreased to 14, below the level of high burden.

Perceived family functioning

Figure 6 shows PCG2 and SCG2's perceived level of family functioning on the GF subscale of the FAD[43] at baseline and week 6.

PCG2's baseline score of 2.08 indicated that she perceived her level of family functioning to be problematic; whereas, her decreased score of 1.83 at week 6 indicated that she no longer perceived her level of family functioning to be problematic. SCG2's baseline score of 1.5 indicated that she did not perceive her family functioning to be problematic and her score stayed the same at week 6.

DISCUSSION

Our findings revealed that 2 family Care

Circles comprising 1 PCG and 1 SCG who used Zalio™ for 6 weeks to coordinate care for a loved one with Alzheimer's disease perceived it to be a usable web-based care coordination app. The effectiveness of Zalio™ at decreasing caregiver burden was variable. Zalio™ had a positive effect in decreasing caregiver burden in SCGs compared to PCGs. Caregiver burden increased in PCGs of both families It is difficult to ascertain whether increased burden is related to the use of Zalio™ itself or to external factors, such as CR2's increase in medical appointments during the study as a result of being involved in a car accident.

No consistent trend was seen in self-efficacy except, surprisingly, both SCGs had less confidence in obtaining respite at week 6 despite Zalio's aim to increase access to help from within a Care Circle. It is questioned whether participants did not realize the potential of the app. A positive trend was seen towards an improvement in perceived family functioning in both PCGs as well as one SCG.

Usability of Zalio™

Zalio's SUS scores across family participants, associated with A and B grades[39], surpass the average SUS score of 77.7 (with a spread of 67.7 – 87.4) that is equivalent to a C grade for the top ten apps, including Google and Facebook, across all platforms (i.e., iPhones and tablets across iOS and Android operating systems[44]. Zalio's high initial training phase ratings in both family cases along with participants' desire to continue using Zalio™ substantiate previous suggestions that onboarding coaches help ease frustration with new technology and increase the likelihood that it will be adopted[22,35,45]. However, participants involved in the study were comfortable using and learning a new technology, which could account for the high SUS scores.

Results from Family Case 1 suggest these family participants may have benefitted the most from Zalio™, in particular, SCG1, who gave it a perfect score. The higher consistent SUS scores in Family 1 may be explained by more frequent use of Zalio™, as perception of usability has been shown to increase with expertise and familiarity[47]. SCG1 lives further away from PCG1 and CR1 than SCG2 to her family, suggesting Zalio™ may be more useful to Care Circle members who are coordinating care from greater distances; however, further research is required. SCG1 is involved solely in general reminders, not with other care tasks such as cooking and shopping that SCG2 performs; therefore, a care coordination tool is particularly well-suited to SCG1's needs. Furthermore, Zalio™ may be particularly helpful to SCG1 who is employed full-time outside of the home and may have less flexibility to restructure her time[48], compared to SCG2 who is a stay-at-home mother. SCG1's comment that Zalio™ is easy to use also supports the assertion that perceived ease of use is what best determines user satisfaction[33].

Privacy concerns revealed by Family 2 support previous literature that cites privacy issues as a frequent user concern[20,27,49]. PCG2 feared that CR2 would find out that she was using Zalio™, as he shared her computer and email address. She was also forced to log onto Zalio™ from her home computer where she was not connected to an external calendar (e.g., Google Calendar) that would enable her to receive updates on her smartphone. Consequently, PCG2 used Zalio™ the least frequently in the study and her concerns may also explain why she was the only participant to have a decreased perception of Zalio™ during the active use phase. Conversely, SCG2 was happy that she could communicate information to PCG2 without needing to speak to her directly. SCG2's perception that Zalio™ was more useful than

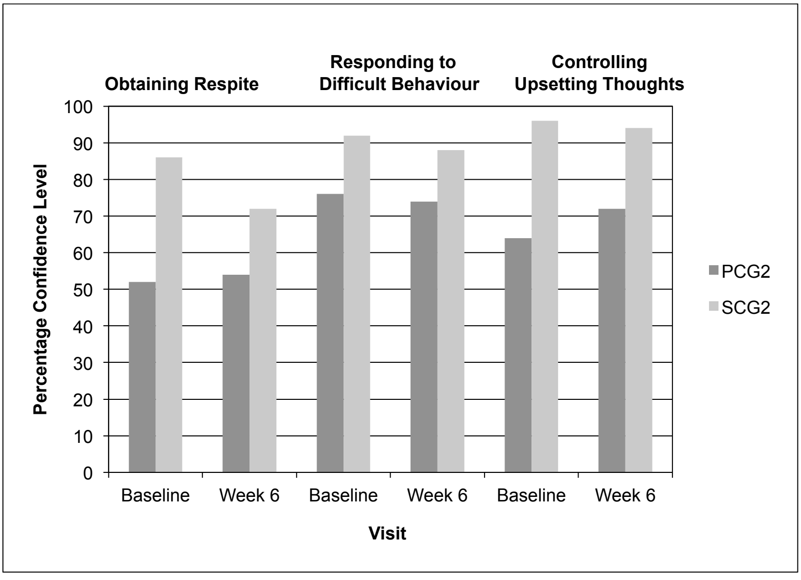

Figure 4. Percentage confidence level in caregiving domains on the revised scale for caregiving self-efficacy[40] in Family 2.

PCG2's perception possibly relates to SCG2's ability to receive updates on her smartphone. SCG2's desire to avoid direct communication with PCG2 may also suggest her own privacy concerns, as CR2 is home most days with PCG2 and there may be limited ability for PCG2 and SCG2 to speak privately.

PCG2's request for an internal Zalio^{TM} calendar is a design consideration. Previous research on family calendar use[50] revealed that family coordination complexities could render technologies, such as Google Calendar, a failure when designed for personal use but aimed at family use. It is possible, therefore, that external calendars may not entirely meet caregivers' needs.

Caregiver burden

Our case study findings of higher rates of caregiver burden in PCGs than SCGs are consistent with previous research showing higher levels of burden in dementia PCGs. High burden in PCGs is usually attributed to a CR's demand on PCG's time, his/her dependency on activities of daily living, and behaviour problems[12]. Similarly, our findings concur with previous literature showing high burden in spousal PCGs due in part to a spouse's older age, poorer physical health, and higher levels of care provision[5]; however, findings differ from at least 1 study that demonstrates equivalent overall global ratings of well-being in PCGs and SCGs[51]. Higher burden rates in Family 2 participants at baseline and week 6 compared to their Family 1 counterparts may be explained by CR2's more rare diagnosis of early onset Alzheimer's disease (≤ age 65) and Family 2 participants' more frequent involvement with caregiving. Additionally, it is likely that PCG2's lack of employment, as well as increased provision of care to her husband who sustained a car accident during the study are contributing to her top burden scores.

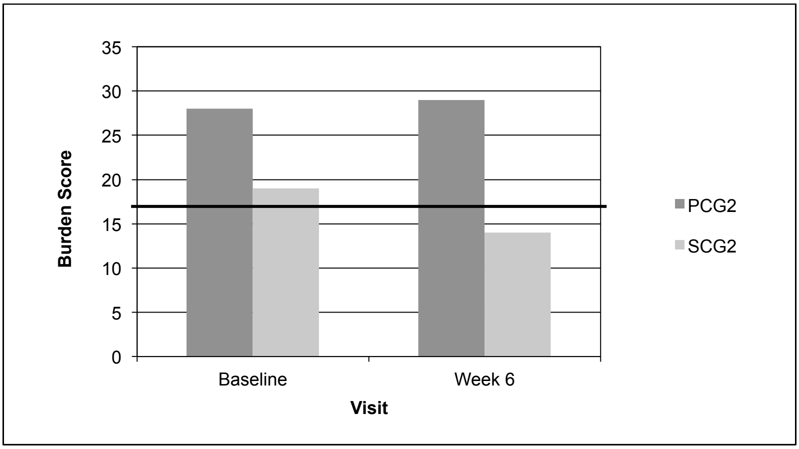

Figure 5. Level of self-reported caregiver burden on the short version of the Zarit Burden Interview (ZBI)[41] in Family 2. Line on figure above indicates a high burden level at n ≥ 17[41].

Zalio's ineffectiveness at lowering burden in PCGs is not unexpected given the short duration of the study. Additionally, variables, such as co-residency, financial burden, and long caregiving hours that are not easily modifiable have been associated with higher levels of psychological stress in PCGs than adult children caregivers[5]. More surprising is our finding that SCGs had a decline in burden levels after the use of Zalio^{TM}, with a notable decline in SCG2 from a level of high burden to low burden. Our results highlight that SCGs can also experience high levels of burden despite being less involved in direct care tasks than PCGs. This finding is supported by research that has found that SCGs can have levels of burden that exceed those of PCGs as they often feel they could be doing more for their relatives[12]. Therefore, it is possible that Zalio^{TM} allows SCGs to feel more involved in caregiving, less helpless, and perhaps less guilty about their situation; however, more research is needed to confirm this finding. Similarly, research suggests a need to understand the role of technology for distance caregivers, as this is a growing segment of the US population. These caregivers take on a large majority of care coordination and transportation tasks and it has been suggested that they may be at even greater risk of anxiety and mood issues than PCGs[52].

Caregiving self-efficacy

Our case studies reveal lower levels of caregiving self-efficacy in PCGs than SCGs, with the exception of Family 1 participants' equivalent baseline confidence levels in obtaining respite. This finding, along with our finding of higher levels of caregiver burden in PCGs than SCGs, coincides with previous evidence that high levels of self-efficacy can help buffer some effects of burden[6-8]. We are not surprised by the variability in levels of self-efficacy in domains not closely related to Zalio^{TM} (e.g., responding to difficult behaviour and controlling upsetting thoughts) or the lack of notable improvement in self-efficacy during our short 6-week study. However, the decline in levels of confidence in obtaining respite that are seen in PCG1 and both SCGs at week 6 is less expected, especially given that Zalio^{TM} is aimed at enabling caregivers to request help from within a Care Circle (e.g., via Activity Coordination). We question whether Zalio™ gives participants more perspective on their caregiving situation, including a better understanding of what other Care Circle members can or cannot offer, leading to more realistic expectations about obtaining respite. It is also plausible that our results are less reliable given that the self-efficacy tool is not validated for telephone administration[40]. However, it is difficult to ignore PCG2's marginal increase in confidence in obtaining respite, and we consider whether it is related to a notable change from a baseline perception of problematic family functioning to a perception of non-problematic family functioning at week 6.

Family functioning

The trend towards an improved perception of family functioning in both family cases suggests that Zalio™ may help Care Circle members feel more connected. It is not known whether this is due to care circle members' having improved communication via Zalio™ features (i.e., Care Wall), members' clearer understanding of each other's roles, or their improved perception of their family functioning for other reasons; however, this trend warrants further investigation. Our finding of higher levels of perceived problematic family functioning and higher burden levels in PCGs compared to SCGs' corresponds with previous literature that family members with poorer perception of family functioning have higher levels of perceived burden[10,11]. In contrast, our findings show that even with improved perception of family functioning in PCGs, their perceived burden levels increase; whereas, levels of burden decrease in both SCGs despite one SCG having no improvement in her perception of family functioning. However, our findings may support previous research that adult children may benefit more from relationship strengthening interventions, such as ways to cope with disagreement between family members; whereas, spousal caregivers benefit more from increased respite[5]. Although further research is required, our preliminary findings support the suggestion that outcome measures of family functioning be included in caregiver intervention studies[10,11], especially considering a lack of good burden measures[22] and difficulty controlling for burden in studies.

Limitations

Our findings are limited to 2 case studies of 4 family participants who are all female Caucasians and whose care recipients are affiliated with one memory clinic; therefore, generalizability is limited. Family caregivers who have the time to join our study may also have less burden and better family functioning than the general population. Usability measurements were repeated in our study to increase the validity of the findings; however, findings are still only limited to caregivers and care-recipients with specific characteristics. We also do not know if participants who have not had direct training on Zalio™ would report the same levels of perceived usability. Our study is also less rigorous as we relied on self-report for how often a participant used Zalio™ during the study, and we were unable to track specific features used or how often each feature was used. The Revised Scale for Caregiving Self-Efficacy has been validated only for in-person administration; therefore, the validity of our self-efficacy results is not known. Furthermore, although we assessed caregiving self-efficacy to respond to difficult behaviours, we did not assess the level of behavioural disturbance in care-recipients that is closely associated with caregiver burden[53]. Response bias is also a possibility as feedback about Zalio™ was given directly to the developer and first author, and participants received a $50 gift card in compensation for their time. Finally, we did not collect formal written comments from participants which is another limitation of our study design.

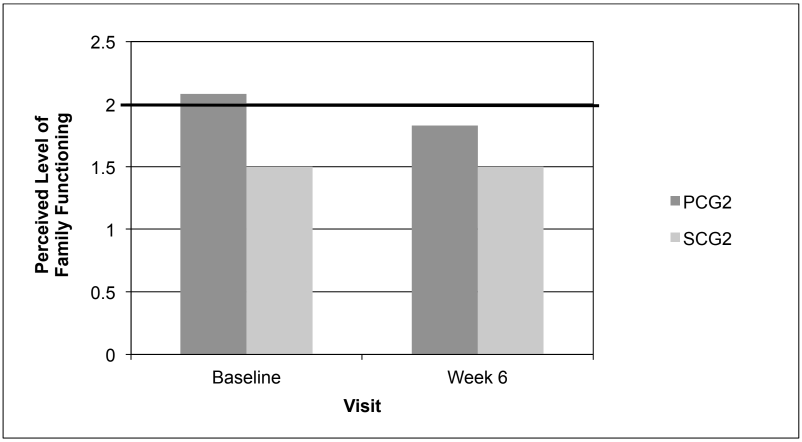

Figure 6. Perceived level of family functioning on the General Functioning (GF) subscale of the McMaster Family Assessment Device (FAD)[43] in Family 2. Line on figure above indicates level of perceived problematic family functioning (n ≥ 2)[43].

Practical Implications and Future Research

Our preliminary findings on the usability of a care coordination app and its impact on caregiver burden, caregiving self–efficacy, and perceived family functioning have important implications and raise valuable questions for future research. Knowledge about the usability of a care coordination app helps guide clinicians with evidenced-based recommendations on technologies that are useful in dementia family caregiving. Practical solutions are needed for dementia caregivers who often struggle to cope with incurable degenerative disease and for whom psychological consequences are high. There are implications for technology design, including the need to consider privacy issues and the benefit of user access to training coaches during onboarding phases, which have been previously cited in the literature. Specifically, for Zalio^{TM}, it is suggested that an internal calendar be considered for users who are not connected to an external calendar. Our research has particular implications for SCGs who have not been a large focus in previous research yet may particularly benefit from care coordination tools. In 2012, over 8 million Canadians were caregivers and over half were caring for an ailing parent or in law[3]. As the population ages and there are more adult children PCGs, care coordination tools may be even more essential as it has been shown that adult children PCGs rely more on SCGs than spousal PCGs[13]. A care coordination tool's ability to improve perceived family functioning is a trend worth replicating especially given evidence of the association with decreased perceived burden[10,11], and family functioning's amenability to change. Our findings also support the need for family functioning outcome measures in caregiver intervention trials.

Future studies of longer duration are required to further determine a care coordination app's effectiveness at decreasing caregiver burden, and to assess sustainability. It would also be interesting to assess whether a care coordination tool could extend the number of people in a Care Circle by enlisting friends and family members who want to help but are uncertain as to how to get involved. Usability studies with alternative care coordination apps are also worthwhile to allow for product comparison and to be able to customize solutions for dementia caregiving.

CONCLUSION

Our results suggest that Zalio^{TM} is perceived to be a usable web-based care coordination app to coordinate care for a loved one with Alzheimer's disease with above average satisfaction ratings. Zalio's^{TM} effectiveness at decreasing caregiver burden is not clear. Further research is required, in particular with SCGs, who may benefit more than PCGs from a care coordination tool. A trend towards improved perception of family functioning in both PCGs and SCGs is intriguing and worth replicating. Further research is needed with larger diverse samples to determine the overall effectiveness of a care coordination tool at decreasing caregiver burden.

Disclaimer

The views expressed in this article are those of the authors and not an official position of the affiliated institutions, funder, or company who provided the web-based application.

Conflicts of interest

There are no conflicts of interests to declare.

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