

Article

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Re-braiding the Strands of Life through Community Rehabilitation, Home Care, and Informal Support: A Longitudinal Collective Case Study

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Résumé

Peu de recherches ont été menées sur les expériences de personnes âgées recevant des soins de réadaptation en milieu communautaire. Notre étude longitudinale de cas collectifs a exploré les expériences des personnes âgées bénéficiant de services de réadaptation et de soins à domicile, ainsi que les perspectives de leurs aidants familiaux. L'approche utilisée est celle de la description interprétative. Des analyses inductives ont été réalisées sur les données recueillies lors de trois entretiens tenus avec six dyades familiales au cours d'une période de trois à six mois. Les questions portaient sur les AVQ, les AIVQ et d'autres activités importantes affectées par des changements de l'état de santé des personnes âgées. L'analyse thématique a permis de dégager trois thèmes : (a) centrer les services communautaires de réadaptation et de soins à domicile sur la personne âgée et sa famille ; (b) comprendre l'interface complexe entre les soutiens formels et informels ; et (c) soutenir les aspects significatifs de la vie. Nos résultats suggèrent un réassemblage, métaphoriquement, ou une reconfiguration des activités nécessitant une intégration accrue des soutiens formels et informels au sein des services de soins à domicile et de réadaptation en milieu communautaire.

Abstract

Limited research exists on the experiences of older adults participating in community rehabilitation. Our longitudinal, collective case study explored older adults' experiences while they engaged in community rehabilitation and home care services, as well as family caregivers' concurrent experiences. Drawing on interpretive description, we inductively analysed interview data gathered at three points over 3–6 months from six family dyads. Questions focused on activities of daily living, instrumental activities of daily living and other meaningful activities affected by changes in the older adult's health. From our thematic analysis, three themes emerged: (a) Centring community rehabilitation and home care services around the older adult and family; (b) Understanding the intricate interface of formal and informal supports; and (c) Supporting the meaningful aspects of life. Our findings suggest a metaphor of re-braiding, a reconfiguration of activities that requires increased integration of formal and informal supports within home care and community rehabilitation.

Introduction

As the Canadian population of older adults increases, some become more frail, and many are more likely to experience chronic conditions (Statistics Canada, 2019). Community-dwelling older adults who live in a private residence are often managing their daily tasks with assistance (Lee & Penning, 2018). Research has demonstrated that experiencing mobility impairments, inability to complete activities of daily living (ADLs) (e.g., bathing, dressing, and toileting), and disease severity are risk factors for long-term care (LTC) home placement in Canada (Rockwood et al., 2004). For older adults, rehabilitation, defined as a set of interventions designed to optimise functioning and reduce disability (WHO, 2017), offers the opportunity to enhance their ability to

live in the community (Luker et al., 2019). Community rehabilitation refers to a type of rehabilitation where the recipient remains living in their private residence and receives rehabilitation services at a location in their community or in their home (Wade, 2003). Closely linked to this concept of community rehabilitation is home care, which consists of trained support workers assisting predominantly with ADLs and certain home-based instrumental activities of daily living (IADLs) (e.g., cooking, laundry, and cleaning). Rehabilitation and home care services support the preference of many older adults to remain living in their community (Wiles, Leibing, Guberman, Reeve, & Allen, 2012), which in turn addresses the goal of reducing costs for the health system (Bauer, Fernandez, Henderson, Wittenberg, & Knapp, 2019).

In addition to formal rehabilitation and home care services, the literature has documented the major role of informal caregivers (often family, friends, and neighbours) in providing significant assistance to support older adults to live independently in the community (Walker, Pratt, & Eddy, 1995). The active support of family caregivers in rehabilitation for those who experience a stroke or traumatic brain injury can be a positive determinant of their recovery (Gbiri, Olawale, & Isaac, 2015; Sherer et al., 2007), however, the role of family/friend caregivers in rehabilitation processes for community-dwelling older adults more generally has received limited attention. As the rehabilitation process for older adults is often longer in duration when compared to younger adults and disease progression often changes abilities (Young, 1996), there is value in understanding the experiences of rehabilitation for older adults and their family/friend caregivers over time.

Over a decade ago, qualitative studies centring around older adults and rehabilitation focused on the meanings participants gave to rehabilitation (Wallin, Talvitie, Cattan, & Karppi, 2007), their perceptions of activity spaces and life satisfaction (Åberg, 2008), and how they perceived staff through time during home-based rehabilitation (Vik, Nygård, & Lilja, 2009). A majority of the studies (Åberg, 2008; Wallin et al., 2007) focused on inpatient rehabilitation, which is different from community rehabilitation. Vik et al. (2009) interviewed three older adults participating in home-based rehabilitation in Norway, semi-weekly over a 6-month time period to understand how participants perceived their interactions with staff. The researchers identified differences and variations in perception of staff, experiences and encounters with staff, expectations for future daily life, as well as needs and tasks relating to their disability (Vik et al., 2009). The findings also indicated that the participants had changing needs throughout the home-based rehabilitation program and it was best if staff engaged in discussion with the older adults regarding: the type of interventions or services needed, expectations of future life, and their changing needs (Vik et al., 2009). The authors suggest that staff tailor their approach for each client in order to achieve a successful rehabilitation encounter.

The most recent qualitative studies on the experiences of older adults receiving community rehabilitation have predominately focused on intervention programs consisting of “reablement”, which is also known as “restorative care” in Canada. Reablement as an intervention is poorly defined (Legg, Gladman, Drummond, & Davidson, 2016) but a recent review article identified essential features of reablement including improving functionality, increasing independence, time limited (6–12 weeks), occurring in home and/or community setting, and being person-centred (Doh, Smith, & Gevers, 2019). Hjelle, Tuntland, Førland, and Alvsvåg (2017) interviewed eight older adults in Norway, half of whom were interviewed 1 month into the reablement program and again 1 month following completion, and the remaining four participants

who participated in a single interview conducted 1 month following the completion of the reablement program. The researchers identified four themes: “My willpower is needed”, “Being with my stuff and my people”, “The home-trainers are essential for me”, and “Training is physical exercises not everyday activity” (Hjelle et al., 2017, p. 1585). A study in the United Kingdom (Wilde & Glendinning, 2012) interviewed 34 service users and informal 10 caregivers in a home-care reablement program without rehabilitation services, as it focused on ADLs with support workers centering around the “doing with” rather than “doing for” approach. The service users and their informal caregivers felt that they benefited from the intervention, however, some service users identified barriers to independence such as lack of ability either through lack of equipment or transportation to leave their home to engage in social activities and the reablement program did offer to help in realising these goals (Wilde & Glendinning, 2012). A recent Canadian study (Compton et al., 2020) interviewed 8 older adults and 11 family caregivers who were involved in a specific program focused on preventing further hospitalizations in crisis cases by providing home care and rehabilitation services short term. The participants were interviewed once and the following themes were identified: “growing older in chosen places with support”, “philosophy of care”, “processes of Home First”, and “significance of Home First for clients and family caregivers” (Compton et al., 2020, p. 436).

Overall, there is limited research that has explored the experiences of older adults participating in community rehabilitation which includes the perspective of their family/friend caregiver. As previously described, studies to date have focused on specific reablement programs, interviews were either non-longitudinal or were longitudinal for the span of 8 weeks, and not all of these studies involved rehabilitation directed by a rehabilitation professional. As such, we have limited longitudinal insight into older adults’ perceptions about community rehabilitation more generally and the extent to which it meets their needs. To begin to fill this gap, the aim of our study was to explore the experiences and expectations of older adults while they engaged in a process of community rehabilitation and home care services over a time period of 3–6 months. Given the major role of family/friend caregivers, we also sought to understand their complementary experiences as they provided care and support during this process. We were particularly interested in how the formal and informal caregivers interacted to support several key aspects of life (ADLs, IADLs, and other meaningful activities) which have been affected when the health status of an older adult within a family changes and that need to be reintegrated.

Methods

Study Design

We conducted a longitudinal study over an average of 4.8 months (range 3–6 months) utilizing a collective case study approach (Stake, 2005) to prospectively understand the experiences of formal home care and community rehabilitation service use among older adults. Specifically, we were interested in learning about the experiences of older adults who, following a health event, were at risk of being unable to continue residing in their home. Methodologically, as the intention of this study was to inform future health system planning for community rehabilitation, we drew on interpretive description (Thorne, 2016). Interpretive description focuses on using the findings of qualitative research studies to inform practice. Our study’s lead researchers represent the disciplines of nursing,

occupational therapy, knowledge translation and rehabilitation sciences, and hold a strong interest in how research findings can be applied to health system transformation. We used in-depth, in-person, interviews to gather data from older adults receiving community rehabilitation services and their family/friend caregivers regarding their experiences at three distinct time periods at selected intervals. Intervals between the three interviews were either 1-month or 2-months in length and were selected based on the changing needs of participants and recruitment challenges.

Setting, Participants, Sampling, and Recruitment

We conducted this case study in Winnipeg, Manitoba which has a population of over 750,000, and where 14.7 per cent of the population is over the age of 65 years (Chateau *et al.*, 2019). This province has the oldest and most established publicly funded home care program in Canada, which includes some rehabilitation services (Shapiro, 1997). Publicly funded community rehabilitation in this health region consists primarily of time-limited programs for specific health conditions (e.g., stroke recovery). We recruited dyads, composed of an older adult and a family/friend caregiver to participate in three semi-structured interviews. The majority of dyads (five) were recruited through a random mailing of study invitation letters to clients receiving home care services from the local public Regional Health Authority. One dyad was recruited through posters displayed in the common areas of assisted living residences. Inclusion criteria for the participants were the following: age 65 years or older; had received home care for a minimum of 3 months; currently receiving occupational therapy (OT), physical therapy (PT), speech language pathology (SLP), or had received any of those services in the last 4 months; had a family/friend caregiver who was also willing to be interviewed; both participants lived in Winnipeg; and both were English-speaking. The recruitment ended when we had reached six dyads as these dyads captured a wide age range and a variety of health challenges. Our study was approved by the Health Research Ethics Board at the University of Manitoba and by the Winnipeg Regional Health Authority Research Access and Approval Committee and all participants provided informed consent to participate prior to each scheduled interview.

Data Collection

Interviews were conducted between August 2018 and February 2019. The older adult receiving services was interviewed first, followed by an interview with a family caregiver, although our criteria included caregivers who were friends, no friend caregivers participated in our study. Participants were offered the opportunity to be interviewed privately or as part of the dyad. Honorariums of \$25 were provided to each participant for every interview and the third interview resulted in an honorarium of \$50 for each participant, as a token of our gratitude for their participation in the study.

As there were interviews at three points in time, the first interview included additional background questions for the older adult, such as their health history and their social history (living arrangements and social activities). All interviews centred around understanding the following: the older adult's functional abilities (ADLs and IADLs) and how they changed through time (interviews 2 and 3); the health care services and community services utilized (e.g., home care and physical therapy); what they liked about the services and what could be improved upon; their role

with the service providers; the type of support received; the older adult's participation outside the home; and the older adults' expectations for the outcome of health services and for their overall future. The first two of the dyad interviews were led by both L.G. and K.Z. and further interviews were conducted solely by K.Z. The interviews were audio-recorded and transcribed verbatim by a professional transcriptionist. The older adult completed a weekly log documenting their health, quality of life, and engagement outside the home, which was reviewed by the interviewer at the time of subsequent interviews to facilitate recall and discussion. As the interviews were 1–2 months apart, the participant's weekly logs were used by the interviewer to ask tailored questions utilizing the information found within the log (e.g., I noticed that for these weeks you were not engaged outside the home, why was that?)

Data Analysis

We drew on inductive thematic analysis (Braun & Clarke, 2006) to analyze the transcripts and create a rich description of the participants' experience. Once all interviews were completed, we uploaded the transcripts into NVivo 12 for data management. Inductive coding on the first 12 transcripts was conducted by J.R. and K.Z. This initial coding phase focused on becoming familiar with the data, exploring and identifying key issues or areas of importance as described by participants. Comparisons between the selection and labelling of quotes were discussed to ensure similar codes were being generated; K.Z. then continued coding subsequent transcripts. To facilitate identifying patterns and unique cases, L.G., J.R., and K.Z. discussed quotes found under similar codes while comparing within and between transcripts. Patton (1999) recommends that qualitative data be organised in different ways to deepen understanding, prompting us to visually organise data for each dyad longitudinally using a case mapping technique to readily depict temporal changes in services and supports. For each dyad, we performed case mapping over four time periods, starting 4 months before initial interview (as recalled by the participants), interview 1, interview 2, and interview 3. The case mapping consisted of creating a quadrant diagram where we situated the formal and informal care/services, as well as the in-home and out-of-home services received at each time point (Figure 1). The case mapping provided the opportunity for the researchers to depict where and when informal and formal supports were present, the nature of those supports, changes to supports through time, and identification of service gaps. This synthesising process contributed to the thematic analysis by highlighting the unstable nature of formal and informal supports through time, as many of the dyad quotes did not readily articulate this temporal or changing aspect of their supports over time. We then visually inspected the case mapping that occurred over time within each case (Figure 1), and then across cases, in order to develop detailed dyad descriptions and create our draft themes, which were discussed and augmented with the research team until all agreed upon the final themes.

To support the development of trustworthiness and credibility of the data (Guba & Lincoln, 1989), an audit trail was kept throughout the analysis, documenting the research process and decisions. In addition, we employed perspective triangulation (Patton, 1999), where throughout the data analysis and interpretation phase, we moved back and forth from a smaller analysis team (K.Z., J.R., and L.G.) to include the larger research team (with backgrounds in family medicine, rehabilitation science, and

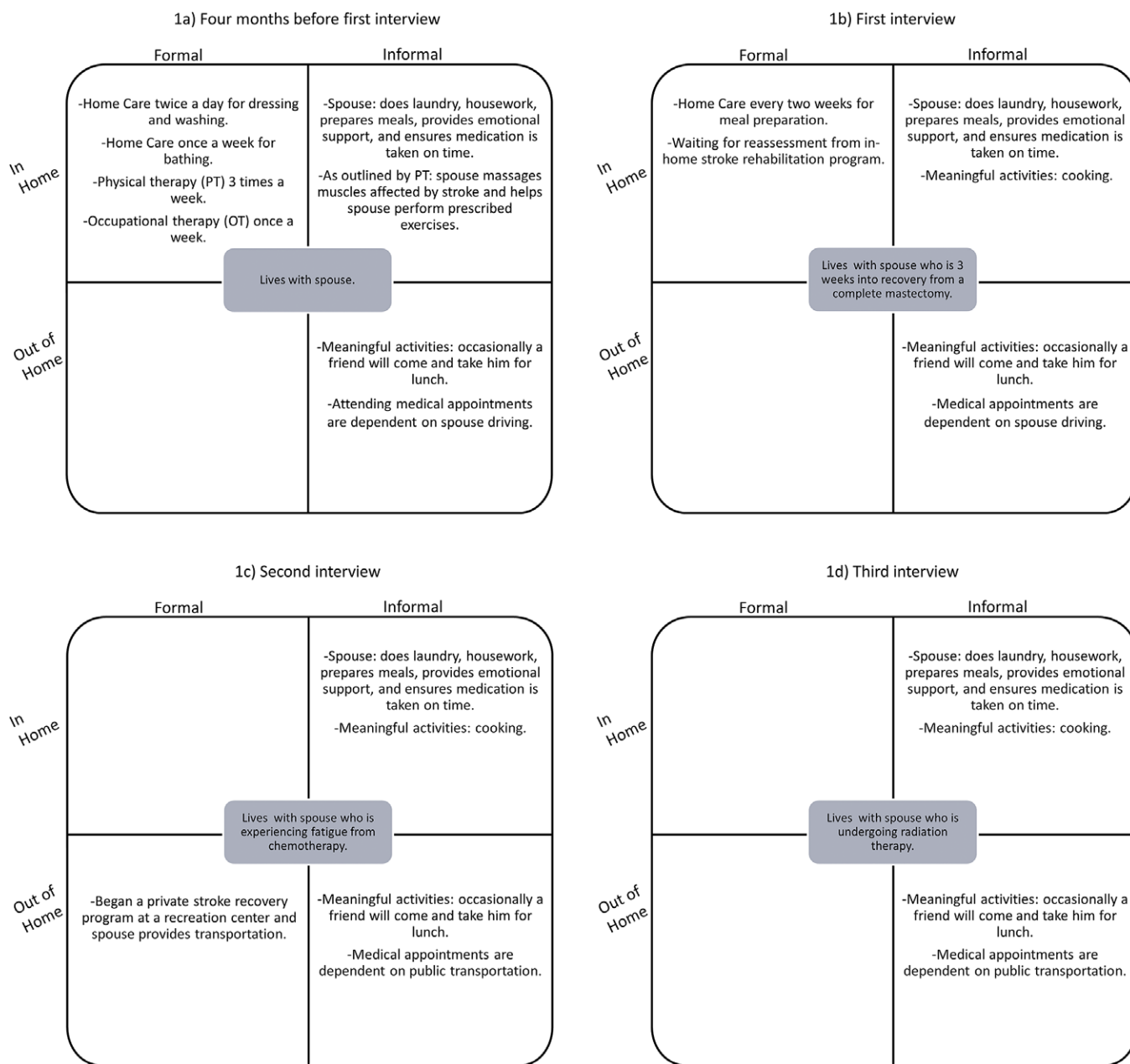


Figure 1. Illustration of case mapping for formal and informal services and/or care through time for Dyad 1.

provincial health systems) to gain a broader perspective on the findings.

Findings

The older adult participants ranged from 65 to 95 years of age (Table 1). All of the older adult participants experienced co-morbidities and five out of six received home care support services in addition to rehabilitation services (Table 1). Five out of six of the family caregivers were female, and four were daughters of the older adult. Interviews with older adults averaged 27 minutes and interviews with the family caregiver averaged 34 minutes in length and all but one dyad participated in all three interviews. Although each participant within the dyad was offered the opportunity to be interviewed privately, all but one selected to be present for each

other's interview and contributed to the interview by providing additional details on specific topics or encounters described.

Overview of Each Dyad

Dyad 1: Albert and Amy

Following a stroke, Albert (pseudonym) was enrolled in the in-home stroke rehabilitation program and received therapy from a rehabilitation assistant as assigned by a physiotherapist, three times a week for 5 months as illustrated in Figure 1a. Albert reported that his rehabilitation program ended when his wife and caregiver Amy underwent a mastectomy (Figure 1b). At the time of the first interview, Albert estimated he spent 20 per cent of his time in his wheelchair and the remaining time he used a cane for ambulation. By the time of the second interview, Albert had experienced an

Table 1. Dyad details (names have been replaced with pseudonyms)

Dyad	1	2	3	4	5	6
Age of older adult, gender, pseudonym	67, male, Albert	80, female, Carol	65, female, June	95, female, Marge	95, female, Odette	91, female, Wendy
Last accessed/ or current rehabilitation service	In-home stroke rehabilitation program and private group exercise for stroke recovery	In-home stroke rehabilitation program	In-home stroke rehabilitation program	Private physical therapy from insurance plan	Early hospital discharge program	Day hospital program
Receives home care service	Discontinued use by second interview	Yes	No	Yes	Yes	Yes
Living arrangement	With spouse, in their own home	Alone, in own their home	With spouse, in their own home	With daughter, in daughter's home	Alone, in an assisted living facility	With spouse, in their own home
Family caregiver's age, relationship, pseudonym	68, wife, Amy	53, daughter, Celine	40, daughter, Jill	60, daughter, Matilda	69, daughter, Olive	91, husband, Willard ^a

^aWillard is the primary caregiver, their adult daughter, "Willow" (pseudonym) was also present for all three interviews with her mother. Informed consent was obtained from Willow.

overuse injury in his hand as a result of providing support to Amy through her cancer journey, resulting in an inability to use his cane with his injured hand, and needing to spend 90 per cent of his time in his wheelchair. After the in-home stroke rehabilitation program ended, Albert found a group exercise program specific to stroke rehabilitation through a fitness centre (Figure 1c). However, due to her cancer treatments, Amy could no longer provide transportation to the program causing Albert to discontinue program attendance (Figure 1d). Amy experienced increasing difficulty with her informal caregiving tasks throughout the study and Albert's ability to assist Amy also decreased through time. Albert's hope for the future was that his hand would be able to recover from the overuse injury.

Dyad 2: Carol and Celine

After Carol's stroke, she was enrolled in the in-home stroke rehabilitation program where she received therapy from rehabilitation assistants as assigned by a physiotherapist, twice a day, 5 days a week for 6 months, and then three times a week once a day for an additional 2 months. When the program began, she needed assistance from home care with dressing, bathing, preparing meals, and house cleaning. During the first interview, she reported using a wheelchair 90 per cent of the time. By the second interview, she stated that her mobility had progressed to being able to use a four-prong cane 60 per cent of the time, and her home care services had decreased to only housekeeping. Carol received the majority of assistance from her daughter, Celine, who delivered prescription medications, brought groceries, washed the laundry, and provided transportation to medical appointments. Carol was dedicated to the rehabilitation program and her goal was to return "back to complete normal health".

Dyad 3: June and Jill

Following a stroke, June received speech therapy three to five times a week for 1 hour from a speech language pathologist through the in-home stroke rehabilitation program. June also reported that she had rheumatoid arthritis that affected her left hand and limited her mobility. She was living with her husband who helped her with cooking, cleaning, laundry and taking medications. Her daughter provided transportation to June's medical appointments, delivered prescription medications, and provided emotional support. When asked about her goals, she shared, "I just keep on trying with words.

I would like the support group [for persons with aphasia]". Throughout the 6 months of the study, June discussed her progression with cooking and at the final interview she shared "I can cook a full meal now". She also described a decrease in anxiety when speaking, yet was unable to participate in a community-based support group for people with aphasia due to it being at full capacity.

Dyad 4: Marge and Matilda

Marge lived with her daughter Matilda who prepared meals, washed the laundry, cleaned the house, and provided emotional support. Marge received privately funded physical therapy to regain the strength she felt she lost over the winter due to lack of physical activity. As a result of arthritis, Marge received home care for dressing and bathing. She used a walker as a mobility aid and her children provided transportation to medical appointments. Her hope for the future was to maintain her strength so that she could continue to live with her daughter and participate in family events.

Dyad 5: Odette and Olive




Following a fall, Odette was enrolled in an early discharge program that provided home care twice a day and therapy three times a week, from a rehabilitation assistant as assigned by a physiotherapist. She lived in an assisted living facility that provided meals, apartment cleaning, and laundry. When she entered the study, the physical therapy Odette had received recently concluded and she reported experiencing physical deconditioning. Her daughter visited daily, delivered prescription medications, and provided transportation to medical appointments, and family events. Odette's future goal was to remain in her assisted living residence. Following the first interview, Odette fell and was admitted to an inpatient facility and was discontinued from the research study.

Dyad 6: Wendy and Willard

Following a stroke, Wendy was enrolled in a day hospital rehabilitation program that occurred twice a week for 3 months. Wendy received daily home care for dressing, and twice weekly for bathing. Wendy's husband, Willard, helped her wash and dress for bed, grocery shopped, cooked, cleaned, and administered Wendy's medication. At the conclusion of the rehabilitation program, Willard began receiving respite support twice a week. The success

During the analysis of data, a metaphor emerged for the older adults and their families—that of a braid of life representing how strands once intertwined became unraveled as a result of a life event, and how they are reintegrated to create a fulfilled, albeit different, life.

Strands in the braid of life

-  IADLs: Instrumental activities of daily living
-  ADLs: Activities of daily living
-  Participation in meaningful activities

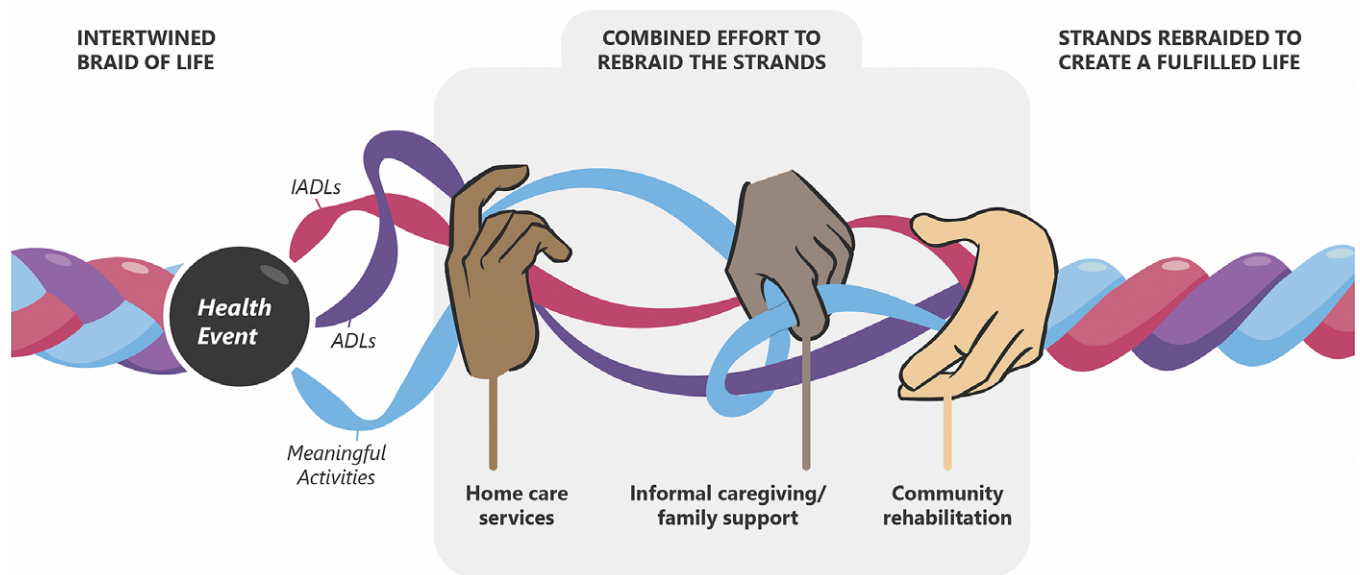


Figure 2. Re-braiding the strands of life.

Wendy experienced at the day hospital program led to her enrollment in a day program for older adults. Unfortunately, the transportation to and from this new program was not accessible, which resulted in Wendy discontinuing the program. Their children provided transportation to medical appointments, and family and friends took them on social outings. Wendy's hope for the future was to remain in her home and she shared, "I hope I don't diminish".

Emergence of a Metaphor

The temporal overview above of each dyad centred around ADLs, IADLs, and hopes for the future, as the older adults spoke of the supports they received in terms of facilitating these particular activities in their lives. The longitudinal aspect of our study helped us understand how an older person's life was disrupted following a health event and the way in which the subsequent supports received assisted in re-forming valued aspects of their life. This understanding led us to develop a conceptual metaphor, the "braid" of life, which we used figuratively to represent how strands of the once-intertwined braid of life became unravelled as a result of a disruption, or changing health status of an older adult within a family (Figure 2). The strands of the braid for the older adults were their ADLs, IADLs, and their self-defined meaningful activities (including leisure, family and community involvement, and social participation), as the participants voiced the need for and appreciation when these areas in their lives were supported. The strands are all of equal width (Figure 2), depicting the equal importance with which participants described these aspects of their lives. Re-braiding the strands of life required the combined efforts of multiple "hands"

(Figure 2), each representing support received from community rehabilitation, home care services, and family/informal caregiving. The re-braiding that occurred was the result of the supports received, and depicted the older adults' perception of a fulfilled life, albeit not the same life, as prior to the health event.

Themes

The conceptual metaphor, the braid of life, demonstrates an interdependency amongst the supports received to assist in re-braiding the strands of an older adult's life. The participants shared how their experiences with supports either facilitated or hindered the re-braiding of their strands of life. Their experiential narratives led to the identification of three themes in the data: (a) Centring community rehabilitation and home care services around the person and family; (b) Understanding the intricate interface of formal and informal supports; and (c) Supporting the meaningful aspects of life. In the following section, drawing on participants' quotes we demonstrate how the themes emerged from the data.

Centring Community Rehabilitation and Home Care Around the Person and Family

The need and preference for partnering with older adults and their families (as defined by the older adult) through appreciating and understanding the personhood (Buetow, 2016) of the older adult were strongly illustrated in our data. Occasions, where formal services took a person-centred approach in rehabilitation or care, were valued by the participants. The older adult receiving rehabilitation

valued person-centred goals made in partnership with the rehabilitation team and caregivers appreciated the opportunity for their loved ones to receive rehabilitation. Albert expressed:

One of my goals was, this summer we had two weddings to go to and I would have to walk on uneven surfaces. So physiotherapy had the rehabilitation assistant walk with me on the grass then walk on concrete.

The “in-home” aspect of the stroke rehabilitation program was valued as it occurred in the participants’ context, thus the individual’s preference for a venue was taken into account. June shared “And when we found out that it [rehabilitation service] went to your house. It was just fabulous”.

While participants appreciated the person-centred approach, they observed that their choices were still limited. Some preferences were not accounted for, as discussed by one older adult and her daughter in their first interview:

Willow (daughter): If they were a little more flexible on the program [home care for dressing and washing].

Wendy: Yeah just, just maybe once let me sleep in.

Willow: She wants them to forget about her one morning a week. But they do the service seven days a week or nothing.

The importance of a person-centred approach was also identified by Willard and Wendy. Following the completion of the day hospital rehabilitation program, Willard received respite services twice a week, from two different personal support workers and each support worker had a different approach:

Willard: I have shown one of them the book that the day hospital program sent home. I don’t like the idea of my wife just sitting in silence with someone when something beneficial could be done in that time.

Interviewer: Did they implement that, or try to do the exercises with Wendy?

Willard: The one that we prefer, does do it. She [Wendy] sometimes says that she is too tired and this person coaches her to do it, which is very good. Once you get going you like doing the exercise?

Wendy: Yeah, yeah, they are not bad once I’m moving.

This scenario highlighted the preference for an approach that is person-centred, where the trained support worker engaged directly with the client to work on activities recommended by the rehabilitation therapists.

Conversely, an inability to consider a holistic perspective of an older adult’s circumstance was counter to a person- and family-centred approach. For example, Albert’s wife, Amy, experienced a health condition that limited the tasks she was able to provide and simultaneously Albert experienced a complete cessation of rehabilitation services and a reduction in-home care services. When Albert and Amy described the cessation of rehabilitation and home care services they originally used the term “mutually decided”. However, Albert also shared that he may not have been in the best state of mind to make such a decision:

Albert: Well the reason that my file was closed [for the in-home stroke rehabilitation program] it was mutually decided that because Amy had breast cancer and she was going to have a mastectomy it was figured, that was going to be enough for us to deal with, we shouldn’t have to deal with my rehab and that.

Amy: I think they would have kept you in the program longer. I mean basically it was stopped because of my breast surgery.

Albert: I got to admit if something happens to your spouse like that it throws you.

When the services ceased, Amy shared the difficulties she experienced in being a caregiver to Albert after her surgery and during her chemotherapy treatments, “I could only lift no more than ten pounds and now with the PICC line being in my arm it is the other arm. I am supposed to be the caregiver but its more him taking care of me”. This led Albert and Amy to meet with a social worker at the Cancer Center who shared that they were not eligible for services. Albert described the following, “the social worker said because her [Amy’s] mastectomy was considered a day surgery there are no services available, even with me having the stroke and limited mobility”. It seems as if services were distributed through a criteria checklist, such as surgery type rather than through a person and family-centred approach.

Overall, this theme demonstrated that participants’ experiences with community rehabilitation services and care that were *centring around the person and family* were positive and appreciated. The instances that lacked a person and family-centred approach emphasised opportunities for current service provision to become person and family centred and that benefit could be realised by using this approach during rehabilitation and home care programming.

Understanding the Intricate Interface of Formal and Informal Supports

In this theme, the fit, or lack of fit, between the needs of the older adult, the specific tasks that family caregivers were willing and able to complete, and the supports provided by the formal services were highlighted. Ideally, informal and formal services should serve to complement or balance each other with emphasis on the formal service completing tasks that the family caregiver(s) was unable to perform. When the ability of a family member to provide informal care fluctuated over time the impact on the older adult dependent on that care was evident.

An example of a well-integrated interface was that experienced by Willard and Wendy, where availability of accessible transportation (for a reasonable fee) to and from a day hospital provided Willard the opportunity for respite while at the same time Wendy was able to benefit from the rehabilitation program location with a gym:

Interviewer: And when your wife was in the day hospital program did that give you some time to catch up with work around the house and go for walks?

Willard: Yeah I shampooed the carpets and stuff like that, that’s awkward to do when she’s home.

Wendy: Oh that was a very nice program, they, they treated us like kings and they were all so good, it was a wonderful program. I could not more highly recommend it to anyone. The physiotherapist did so much with me.

The timing of changes affected the interface of formal and informal supports. Carol (Dyad 2) received in-home stroke rehabilitation service twice a day, 5 days a week, for 6-months, followed by rehabilitation services once a day, three times a week, for an

additional 2 months. The stepped reduction in services was perceived by Carol to have been done in a manner that was timely and provided an ideal interface for managing the completion of formal services. When asked if Carol was worried about the ending of services she shared at the final interview, "Not at this point because some of the exercises I can do on my own".

Other participants experienced a lack of fit between formal services and the family caregiver's (in)ability to perform certain tasks. Olive expressed the following gap in the first interview:

I cannot do showers. I don't have the strength, I don't have the knowledge of the handling of it, I cannot do that. So like she [Mom] didn't get a shower this morning because nobody showed up and I just said to her 'Mom, I can't do that for you'.

Odette and her daughter, Olive, experienced a lack of communication and dependability from an early discharge from the hospital program. Olive expressed her frustration as follows, "I find that there's no follow-up, this is the second time they didn't come to provide a shower". Additionally, Olive shared "My hopes and dreams for this [program] are that I won't have to phone every time to find out who's going to be looking after her and when they're coming".

Following the completion of the day hospital rehabilitation program, Wendy was enrolled in a publicly subsidised day program for older adults. However, the pick-up transportation provided to get to the day program did not provide the physical assistance Wendy required to get on the bus with her walker (whereas the day hospital rehabilitation program provided assistance on and off the bus). This lack of accessibility caused them to discontinue the program:

Willard: Well the drivers not responsible to help them in anyway, not at all, and when she went out to the vehicle, the fellow just stood back and I called to him, I said she could need some help 'cause she got to her walker, but she has to get up the steps.

Willow (daughter): Yeah, so we felt that any advantage she got from the program didn't outweigh the risk of having a potential fall and breaking a hip.

The theme, *Understanding the intricate interface of formal and informal supports*, revealed that a combination of both formal and informal supports was utilized by all the participants throughout the study. However, it also demonstrated how formal supports should seek to understand and complement the abilities of the family caregiver in order to fit to meet the needs of the older adult in a delicate and changing interface.

Supporting the Meaningful Aspects of Life

The participants in our study shared how rehabilitation gave them the strength to engage in meaningful activities, but simultaneously voiced their dependence on informal supports for engagement outside the home. They expressed their ongoing desire to engage in activities and social relationships that they found meaningful. This theme describes the importance participants placed on remaining in the community, participating in activities, and engaging in their valued social networks. This theme also highlights the role formal services play in supporting older adults to engage in and maintain the meaningful aspects of their life.

Participants desired to remain in their current living arrangement and avoid LTC home placement. In her final interview, Marge expressed:

I would like to stay with my daughter. If I need anything else, I hope home care can provide me with that help, that assistance throughout my years. I would like to stay the same with what I can do, I do not want to get worse. And I don't ever want to go to a nursing home.

Family caregivers in our study voiced similar sentiments:

Olive: Its, its about her integrity, her individuality and I seriously think she'll get more care [here] than if she was in a personal care home, it's nicer care. So, it's all about her and what makes her happy.

Participants also shared how building and maintaining strength was necessary in order to engage in meaningful activities:

Marge: I last had physiotherapy in the Spring this year. The winter was tough on me and I needed to get my strength for summer, for my ninety-fifth birthday. You know building strength in seniors is important.

Odette reported she had received therapy from a rehabilitation assistant as assigned by a physiotherapist in the month prior to entering our study. Once the therapy ceased, she noticed a decline in her ability, "I can barely walk inside now that they [rehabilitation assistant] stopped coming". Previously, walking was an activity Odette enjoyed. Additionally, family caregivers valued physical therapy for their loved ones even when it was not publicly funded, Matilda shared, "She is able to keep up her strength you know and by having the services, like the physical therapy."

Both family and friends provided transportation to participate in meaningful activities and social relationships outside the home. For example, Wendy shared, "And I have all the entertainment I need because my family takes me out, if it wasn't for them taking us out we wouldn't get very far 'cause we don't have a car". When the caregiver was unable to provide transportation, it had a significant impact on the activities of the older adult. Albert shared, "But she's got cancer, half of the time she's too tired to take me. So, you know I'm basically housebound". As a result of the caregiver's situation, Albert was dependent on the public accessible transit program, which he experienced as unreliable. He shared:

Every time I've gone to get them to pick me up they've been late, or could only drive me one way and can you imagine somebody that's handicapped and let's say you're at the Fitness Centre, you're taken to a class at the Fitness Centre, my stroke rehab, can you imagine telling a person you can pick them up and get them there but can't get them home, what the hell am I supposed to do?

Older adults in our study shared that they valued being supported to participate in activities they enjoyed both inside and outside the home. In order to participate in activities inside the home, family members supported the older adult by delivering the necessary supplies. June shared, "Jill delivers the kid's books to me, to get my reading back up". Marge, expressed, "I've done crocheting, I've done dish cloths and I've done two scarves and I'm going to make some headbands. My other daughter picks the yarn up for me". Additionally, Marge, expressed how she was dependent on her family for all activities, "Well I'm not really engaged in the community at all now except for family".

The theme *Supporting the meaningful aspects of life* demonstrated the role of formal services in providing the opportunity for participants to stay in their ideal living arrangement, as well the necessity of family and friends helping to complete IADLs and support other meaningful activities. Rehabilitation offered the opportunity for the participants to rebuild their physical strength in order to engage in meaningful activities. Furthermore, the resumption of meaningful activities in the lives of the participants seemed dependent upon friends and family and was a highly valued aspect of an older adult's life.

Our study results identified that IADLs and meaningful activities were most often supported by family caregivers and if/when the caregiver was no longer able to provide support, these particular strands unravelled. This was clearly demonstrated in the situation where Albert's wife could no longer drive him to his stroke recovery exercise sessions and he discontinued the program. The inclusion of IADLs and meaningful activities in Figure 2 brings to the forefront the value older adults' placed on these strands in their life and suggests to service providers and health systems leaders that expanding services beyond supporting only ADLs is essential.

Discussion

Engaging with, and following, the older adults and their families during the study provided us the opportunity to document the changes in their needs and abilities, and their experiences with community rehabilitation, home care services, and their interactions with their informal caregivers. Five of the six older adults experienced a major health event (stroke or fall) and one experienced deconditioning as a result of arthritis, and all of them had at least one family member who provided support.

Our first theme, *Centring community rehabilitation and home care around the person and family*, acknowledged both the need for formal health services that are person and family centred and the value that families placed on this approach. Families identified formal services utilizing this approach as "fabulous" and the supports provided as "very good". Families also observed that some services could be a "little more flexible". Home-based rehabilitation was valued by the participants, in support of other research that demonstrated home-based rehabilitation was as effective as hospital-based rehabilitation (Parker et al., 2011; Ward, Drahotka, Gal, Severs, & Dean, 2008). Family- and person-centred care for older adults have been investigated in terms of health care decision making (Wolff & Boyd, 2015). There are systemic barriers in implementing family-centred care, however, a review (Bamm & Rosenbaum, 2008) found that the political hurdles can be overcome with strong leadership, the financial consequences are positive, and attitudinal factors amongst health professionals are likely the result of lack of education and research supporting this perspective.

An example where community rehabilitation and home care services did not center around person and family involved Albert and Amy. Initially, Albert received home care services for ADLs and IADLs (dressing and washing/bathing, and meal preparation), and stroke rehabilitation services (physical and occupational therapy). Amy was Albert's caregiver, providing support in IADLs (laundry, taking him to medical appointments, medication monitoring, housework), preparing meals together (a meaningful activity), and augmenting physical therapy as outlined by the physical therapist. However, rehabilitation services were discontinued for Albert (with consequential deconditioning) because Amy was diagnosed with breast cancer. The roles were reversed and Albert

became Amy's caregiver, subsequently experienced an overuse injury to his hand that decreased his ability to ambulate with a cane and led to an increase in time spent in his wheelchair. In a preferred situation, community rehabilitation and home care services that were centred on Albert and Amy would have re-assessed the change in Amy's health status and Albert's desire to be her caregiver, and then implemented a revised health service plan that met changing needs and family support resources. Several questions were raised in their circumstances: "What could have been improved upon in order to re-braid the frayed strands of Albert's and Amy's life?" "Did the cessation of community rehabilitation mean that Albert no longer needed care?" and "After Amy's surgery (mastectomy) and treatments (radiation and chemotherapy), should restorative care have been initiated for her?" Many years ago, Twigg (1989) suggested that community models of care tended to view a client's family as sources of information or co-workers, but less often as co-clients. Albert and Amy's circumstances reflect this assertion.

Our study results point to the need to better integrate community rehabilitation and home care services. Home care services served an important role in augmenting the ability of the individual when they could not perform ADLs and some IADLs. However, home care tended to take a "do for" rather than a "do with" approach touted by community rehabilitation (Metzelthin et al., 2017). Our study findings suggest that health systems must consider these services on a continuum, and provide intentional and shared decision-making with older adults and their families about the desired balance of replacement versus reablement support provided. For this initiative to be successful, home care support workers will need to be trained in reablement approaches and care plans that clearly articulate reablement goals, incorporating all formal and informal support partners in the planning. This need for integrated interdisciplinary team training has been identified by leaders in geriatric medicine, who specifically identify the need for services to be flexible in response to changing circumstances (Montagnini et al., 2014). While the existing literature has supported the partnership between community rehabilitation and home care support services in terms of specific reablement/restorative care programs (Aspinal, Glasby, Rostgaard, Tuntland, & Westendorp, 2016; Doh et al., 2019), little has been done to examine this in terms of health systems wide initiatives.

Our second theme, *Understanding the intricate interface of formal and informal supports*, identified the relationships within formal health services (home care support services and community rehabilitation) and between these services and the informal supports of family caregivers. This is similar to the findings of a study that focused on family caregivers and found that the systems of formal and informal care are inexplicitly interconnected (Sims-Gould & Martin-Matthews, 2010), however, we were unable to locate any literature that describes implementation of this understanding at the health system level. As illustrated in Figure 1, for Albert and Amy, the two quadrants of formal services lessened and disappeared while the two quadrants of informal or family support continued to change. Generally speaking, the relationship between formal services and family supports was integrated at times but not consistently within and across family experiences. Willard and Wendy's experience of integrated care was positive, in particular, with safe transportation to and from the day hospital rehabilitation program where Wendy participated in physical therapy, while Willard experienced respite.

The Task-Specificity model described by Litwak (1985) suggests that supports must be a "fit" with needs, and that type of specific tasks varies between and among formal services and family

support. In our study, some strands of the braid were only provided by family, whereas other strands were provided by formal services. Examples from our study include when older adults identified their family members and friends as providing emotional and “hands-on” support. June said that her daughter Jill provided transportation to medical appointments, delivered prescription medications, and provided emotional support. As illustrated in Figure 1, for Albert and Amy, friends and family provided support for out-of-home social events. Similarly, family caregivers may not be equipped to provide supports that are considered specific to formal services expertise or skill set (Ward-Griffin, 2002). Recently, a new singular care program in Saskatoon demonstrated excellent fit between informal and formal services (Compton et al., 2020). However, in our study when the home care support worker did not come as scheduled to provide a shower for Odette, her daughter Olive said she could not substitute this assistance because she did not “have the strength”. Although Olive visited daily, delivered prescription medications and took her mother to medical appointments and family events, she was not physically able to bathe her mother. When a breakdown in formal health services occurs, it seems that primarily the ADL strands in the braid of life are interrupted and the intricate relationship between formal services and family support is affected.

Our third theme, *Supporting the meaningful aspects of life*, relates to how older adults described the meaningful aspects of their lives when asked about their goals for the future. Predominately, the answers were about staying in their current living arrangement in the community, maintaining their physical strength, and staying engaged in activities. Marge wanted stability and no relapse, “I want to stay the same with what I can do, I do not want to get worse.” Marge’s daughter, Matilda said, “She is able to keep up her strength, you know and by having the services, like the physical therapy.” Odette observed her decline in walking ability once rehabilitative services were discontinued. These experiences align with the findings of systematic reviews that identified that physical exercise therapy for older adults has benefits (Giné-Garriga, Roqué-Fíguls, Coll-Planas, Sitjà-Rabert, & Salvà, 2014), particularly by improving and maintaining mobility (de Vries et al., 2012). Our study findings seem to suggest that maintaining physical function was a key aspect for the participants, although not all services provided this aspect for the long term. Functioning has been referred to as a third health indicator in addition to mortality and morbidity (Cieza, 2019; Stucki & Bickenbach, 2017), and as the sixth vital sign (Richardson et al., 2012; Williams & Law, 2018). We suggest that a reframing of rehabilitation services at the health system level is needed to support older adults in maintaining their function.

Older adults also emphasised the importance of family support in achieving their goals, and in terms of meaningful aspects, they described the value of being accompanied to appointments and social events. Transportation and particularly, the lack of safe and reliable formal services in transportation was a common observation. When family members could no longer provide transportation to appointments for physical therapy, it meant the end of out-of-home physical therapy for Albert. This account echoes a review of studies that concluded transportation access is a significant barrier to health care (Syed, Gerber, & Sharp, 2013). Wendy was concerned that without the support of family and friends, some of the activities she enjoyed might cease. She said, “Oh no, not the activities I have. If they give up on me that would be terrible”. Wendy’s statement has transferability, as previous qualitative research with older adults has described the lack of interaction

with social networks and activities when transportation is not available (Adorno, Fields, Cronley, Parekh, & Magruder, 2018). Furthermore, the World Health Organization (2007) described transportation as a key factor in whether an older adult receives health care and participates in social activities.

Our study highlighted the valuing of social care by older adults and their families, as it is this care that provides access to meaningful activities and social relationships, which are vital to health and well-being (National Academies of Sciences, Engineering, and Medicine, 2020). Vlachantoni (2019) identified that there is unmet need for social care for older adults (Vlachantoni, 2019). Recently the concept of integrating social care (access to transportation, meals, and housing) into health care delivery has been strongly suggested (Bibbins-Domingo, 2019).

Our findings, illustrated through the metaphor of the braid, support this notion, that is, that health and social care for older adults are intertwined. Furthermore, the three themes identified in our study can flow into the re-braiding by serving as guiding principles for home care and community rehabilitation to successfully support the re-braiding of an older adult’s strands of life. The metaphor of the braid can be utilized by service providers and health system leaders to deepen their understanding of the interdependence between home care services, informal caregiving/family support, and community rehabilitation that support the re-braiding of the strands of life (Figure 2).

Limitations

The limitation associated with qualitative research is that the findings may lack transferability in understanding phenomena in other jurisdictions. However, we provide detail on context and services that increase the transferability of the findings. Four of the six older adult participants had experienced a stroke as this was a population of older adults engaged in community rehabilitation and thus easily accessible for recruitment to our study. This limits the results being transferrable to older adults who have not experienced a stroke. However, specialised programs for persons who have experienced a stroke are not uncommon as there seems to be greater a concentration of public rehabilitation services for diseases considered in the biomedical model, versus other chronic conditions (Wade, 2015). Additionally, the landscape of the funding mechanism for community rehabilitation in Canada is complex, as such, this study recruited participants who accessed privately or publicly funded rehabilitation therapy. As per our inclusion criteria, each older adult participant needed to have one identified informal support person as a co-participant. The situation experienced by older adults who do not have an available informal support person in their lives is unknown, but is postulated to be more challenging than those experiences shared by our participants, given the crucial role of the informal support persons in our study. Nevertheless, these findings provide a holistic perspective of how a health event creates a disruption for both the older adult and their informal family caregiver, necessitating support from community rehabilitation and home care services.

Conclusion

Our study highlights the valuing of community rehabilitation, home care services, and informal support by older adults and calls for increased integration of these supports to facilitate the re-braiding of the braid of life. These qualitative findings serve

as supporting evidence for system-level changes intended to strengthen a holistic vision for community rehabilitation, home care services, and social care, in the health care delivery for older adults. Health system leaders, policy makers, and service providers will be better positioned to deliver health services if they gain an understanding of how the integration of services and informal care are fundamental to supporting the ADLs, IADLs, and the meaningful activities in an older adult's life.

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