Patient and Family Caregiver Experience with a Collaborative Care Pilot Project to Support Seniors Managing Multi-Morbidity in a Primary Care Setting

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ABSTRACT

This study reports findings from an evaluation of a 3-year collaborative care pilot project implemented in a Canadian primary care setting to assess and treat seniors (age ≥ 65) living at home with a chronic physical

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illness and co-morbid depressed mood or anxiety. Data were collected using semi-structured interviews with seniors and family caregivers who had participated in the project (*n* = 14). Descriptive qualitative analysis revealed the significance of the care manager's role in offering social and emotional connection and non-stigmatizing support to seniors living at home and self-managing their physical and mental health.

Keywords: multi-morbidity, co-morbidity, seniors, collaborative care, primary care, care management, geriatric mental health

RÉSUMÉ

La présente étude rend compte des résultats d'une évaluation d'un projet pilote triennal de soins offerts en collaboration dans un contexte de soins de santé primaires au Canada destiné à évaluer et à traiter des personnes âgées (65 ans et plus) vivant à domicile et souffrant d'une maladie physique chronique et de troubles dépressifs ou anxieux concomitants. Les données ont été recueillies au moyen d'entrevues semi-structurées réalisées avec des personnes âgées et des aidants naturels ayant pris part au projet (*n* = 14). L'analyse qualitative descriptive a révélé l'importance du rôle du gestionnaire de soins dans l'établissement d'un lien social et émotionnel et l'apport d'un soutien non stigmatisant aux personnes âgées vivant à domicile et gérant eux-mêmes leur santé physique et mentale.

Mots clés ： multimorbidité, comorbidité, personnes âgées, soins en collaboration, soins de santé primaires, gestion des soins, santé mentale gériatrique

Multi-morbidity—the co-existence of two or more chronic physical and/or mental health conditions—is a complex medical reality particularly prevalent amongst seniors (Pearlman, 1991). It is associated with an increased risk of mortality and decreased daily functioning (Boyd & Fortin, 2010; Salive, 2013). Seniors living with multi-morbidity are more likely to experience mental health issues such as anxiety and depression (Clarke & Currie, 2009; Jones, Amtmann, & Gell, 2016) and decreased quality of life (Fortin et al., 2004; 2006a; Wikman, Wardle, & Steptoe, 2011), necessitating a substantial psychosocial component to effective multi-morbidity care and self-management support (Bayliss, Ellis & Steiner, 2007; Rijken et al., 2005).

Multi-morbidity is increasingly managed within primary care settings (Fortin et al., 2006b; Van der Akker et al., 1998). Physicians caring for patients with multi-morbidity, however, face a number of challenges, including incompatible funding models and a lack of clinical practice guidelines appropriate for co-existing conditions (Fried, Tinetti, & Iannone, 2011; Mulvale, Danner, & Pasic, 2008; Sunderji, Ghavam-Rassoul, Ion, & Lin, 2016; Upshur & Tracey, 2008). The prevalence of mental health conditions among patients suffering chronic and multi-morbid illnesses also necessitates mental health care to be provided within primary care, despite current limitations in doing so. General practitioners (GPs) are not always adequately trained or resourced to assess and treat a high volume of mental health issues (Kates, 2017; Thota et al., 2012) and research shows mental health conditions are frequently under-identified, under-treated, and under-prescribed within primary care (Birrer & Vermuri, 2004; Craven & Bland, 2013; Orrell et al., 1995). As adults aged 65 years and older are expected to flood primary care in Canada within the next two decades (Craven & Bland, 2013), it is increasingly crucial to develop successful care models to support patients, families, and healthcare providers in the co-management of multi-morbidity in primary care settings (Gil et al., 2014).

Collaborative care is one model that has emerged in response to the challenges of managing multi-morbidity (Katon et al., 2001; 2010). This type of integrated care functions primarily on systematic case reviews amongst inter-professional teams including primary care physicians, mental health specialists (typically social workers as well as psychiatrists or psychologists), and care managers (often social workers and nurses). The model leverages the knowledge and cost-effectiveness of inter-professional teams to offer specialized and person-centred care through the generation of integrated care plans and shared decision-making (Coventry et al., 2012; Kates et al., 2018; Morgan et al., 2013). Care managers are central to this model, for both system navigation and therapeutic intervention liaising between care teams and patients, working on problem identification and goal setting to support patient self-management (Bullock, Waddell, & Wilson, 2017; Gunn et al., 2006).

Studies indicate collaborative care can be effective in the management of multi-morbidity amongst elderly patients (Overend et al., 2014; Unutzer et al., 2002; Von Kolff et al., 2011). Most existing research focuses on depression in seniors with diabetes and further work is needed to understand its use in managing other mental and physical health conditions (Dham et al., 2017). Successful implementation of collaborative care still faces challenges on the ground, such as poor inter-team communication and professional siloes in healthcare practice (Wood, Ohlsen, & Ricketts, 2017). It is important to understand how collaborative care models function across different healthcare systems, patient populations, and local settings so they can be effectively developed for context-specific needs and structures (Tinetti, Fried, & Boyd, 2012). It is also essential to examine patient experiences with interventions informed by collaborative care to understand how certain components work to meet patient needs.

Building on existing research and practice, a 3-year pilot project called the Community-Based Seniors (CBS) project was designed using elements of the collaborative care model and implemented in a primary care setting to help assess and treat seniors living at home with multi-morbidity. The project design included biweekly assessments over a 6-week or 16-week period and the main component was a weekly structured case review comprising a geriatric psychiatrist, a geriatrician, a primary care practitioner, and the care manager. Care managers first assessed each patient's overall health and functioning in the home to determine enrollment in the CBS. Upon enrollment, care managers presented each case for therapeutic recommendations from the team regarding both the physical and mental health conditions of the patient; they would then liaise with the patient's primary care practitioner who remained the most responsible physician for the treatment of the patient throughout enrollment. The care managers carried out home visits to assess response to treatment and provide a psychotherapeutic intervention. Additionally, care managers supported medication adherence, provided information and resources, helped with healthcare system navigation, identified patients' care goals, and gathered information to inform an integrated care plan developed via the structured case review. The CBS's therapeutic intervention includes a stepped psychotherapy intervention called Engage, which is informed by behavioural activation therapy to support the management of anxiety and depression in seniors (Alexopolous & Arean, 2014; Alexopolous et al., 2016). Plans to scale beyond this initial pilot phase include a "hub-and-spoke" model to recruit community partners to provide their own care managers while being supported via this project's systematic care review processes and specialists.

The project's design drew on principles of collaborative care laid out by the AIMS Center of Advanced Mental Health Solutions at the University of Washington, including the use of a patient-centred care team,

measurement-based treatment to target, and evidence-based care[1]. The project was not informed by the accountable care principle—meaning accountability and reimbursement for quality of care and services, not just quantity—as reimbursement was carried out according to the billing regulations of the Ontario fee-for-service healthcare system and project stipend support for the team members. The CBS is one of multiple projects conducted by the Medical Psychiatry Alliance (MPA) in Ontario, a collaborative partnership among three hospitals (community, psychiatric, and paediatric) in the Greater Toronto Area (GTA). The MPA's aim is to develop, implement, and evaluate new models of care that integrate physical and mental health services.

This article reports findings from a qualitative evaluation of the CBS. The findings are intended to contribute insight into patient and family caregiver experiences with a collaborative care project to inform the design of future interventions. Patient perspectives are essential for building patient-centred strategies that effectively respond to the complexities of managing multi-morbidity in elderly populations living at home and finding support in primary care.

METHODOLOGY

Study Design

This study was designed based on descriptive qualitative methods (Sandelowski, 2000). The objective was to examine patient, family, and healthcare provider perspectives on a collaborative care model, informed by the contextual factors related to project implementation. Here we report on the experiences of patients and family caregivers specifically; findings from healthcare provider data are reported elsewhere.

Study Setting

The CBS was conducted at Trillium Health Partners (THP), a large community teaching hospital. Primary care physicians referred patients who were community-dwelling seniors (age ≥ 65) experiencing a chronic medical condition and depressed mood or anxiety. The project was designed for outpatients identified as the rising-risk; i.e., those who had none or minimal previous contact with the mental health care system.

Recruitment and Sample

Ethics approval was obtained from THP's Research Ethics Board. The project received 332 referrals between June 2017 and June 2019. Of the 332 referred patients, 212 were enrolled and 187 completed the program. Recruitment took place in the second pilot year (2017) from a population of approximately n = 72 patients at that point. A convenience sampling approach was taken, in which care managers provided patients the opportunity to sign a Consent to Contact form upon discharge, and *n* = 17 patients signed this form. The research coordinator was unable to contact *n* = 3 by the email and/or phone number provided. The final sample was *n* = 14 participants, including *n* = 11 patients and *n* = 3 family caregivers. (Table 1). After informed consent was obtained, interviews were scheduled at the participants' convenience.

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1. Source: https://aims.uw.edu/collaborative-care/principles-collaborative-care

Table 1

Sample Characteristics

Demographics		Patient Participants (P) ($n = 11$)	Family Care-Giver Participants (FCG) ($n = 3$)
Sex	Male	6	0
	Female	5	3
Age range	40–49		1
	50–59		
	60–69	2	
	70–79	6	2
	80< years	3	
Marital status	Single	2	
	Married	6	3
	Widowed	3	
Education level	High school	2	
	Diploma	4	
	College diploma	2	2
	Undergraduate	1	1
	Advanced degree	2	
Household income level	50,000–74,999	4	
	75,000–99,999	2	
	100,000<	3	2
	Declined to respond	2	1
Self-identified ethnic/ cultural background	Caucasian/Western European	11	3

Data Collection

An experienced qualitative researcher (SM) conducted all of the semi-structured interviews within one to six months of the patient completing the program. The interviews were 30–60 minutes in length. All of the caregiver interviews were conducted by phone; $n = 9$ patient interviews were conducted by phone, and $n = 2$ patient interviews were conducted in person at the senior's home. A common interview guide was used for patients and family caregivers, with topic areas including (1) the patient's background as it related to their involvement in the project, (2) their understanding of the project's components and their experiences in the project, and (3) how they would want to see the project improved or expanded. The interviews were audio-recorded, transcribed, then reviewed for accuracy and de-identification. The reviewed transcripts were entered into Atlas-Ti, a qualitative data management software program.

Data Analysis

The researchers conducting the analysis (SM, PD, MM, EM) are collectively trained in scientific and social scientific fields and have applied experience in health research using quantitative, qualitative, and mixed-method design. These four team members independently open coded a purposive sample of transcripts to develop potential coding categories. A coding framework to support analysis was established and iterated through further in-person meetings while three research team members (SM, PD, MM) coded the remaining interviews. Two qualified members of the research team experienced in qualitative analysis (SM, EM) reviewed completed code reports to identify patterns of meaning within and across the data. Memoing and discussion took place throughout the coding and interpretation process to enhance rigour in the findings through self-reflexivity and transparency. The two researchers met for in-person analysis meetings to discuss similarities and differences amongst the interviews and develop emerging themes that were subsequently reviewed by the larger qualitative team. These meetings also included discussions on our position and location as researchers and how it might affect both data collection and analysis.

RESULTS

Four key themes were identified across the data: (i) participants valued the personalized attention and social connection they received from the care managers, (ii) participants perceived the project as providing access to mental health care in a resource-scarce system, (iii) participants valued non-judgmental support for meeting care goals, and (iv) participants desired a longer program and/or ongoing contact with care managers. A description of these themes along with exemplary quotes are provided below.

Participants Valued the Personalized Attention and Social Connection Received from Their Care Managers

Participants frequently focused on interactions with their care managers when describing the project's core components and benefits. While access to psychiatric care was important to many, having someone readily available to talk to and listen attentively to their concerns emerged as the project's most meaningful feature. The project's personalized approach was seen as fostering open, equitable, and personal dialogue between patient and care manager. The care managers' dispositions were highlighted here, as participants described them as pleasant, warm, engaged, and caring individuals.

Having the visits take place in the home contributed significantly to participants' comfort level; the environment was familiar, less distracting, and more conversational than it would be in office settings. Home visits also reduced the stress of travelling to and parking at the hospital:

> …it was in-home visit, which made it quite convenient instead of having to, obviously—it's one less thing for [my spouse] to drive me around to and whatnot, so that was pretty nifty. (P7)

Although participants did not describe the home visits as a form of therapy, they observed therapeutic elements of the ongoing conversations they had with care managers in that setting:

> But she came in and we sat together and she listened to what I had to say…And I told her a little bit about my past history and how I was dealing, and of course that is good, that is excellent. Because when she

left, I felt really very good, just unloading, it's amazing. And I don't think I'm very different than a lot of people. (P1)

Well [the visits] helped me, yes, because I was talking. And they give you hope, you know? And they tell you what to do and that you should go out. (P10)

For many, the home visits became something to which they looked forward: "I was just happy to see her at the door when she came" (P6). Participants spoke of social isolation (i.e., the absence of contact with other people) and loneliness (i.e., feelings of social deprivation) in relation to their mental health and the benefits of having someone to talk to:

Living alone is probably also a part, where you are alone with your thoughts, so you chew up more and more. You kind of lose a little bit of optimism. (P5)

…As far as the mental health aspect, you know I feel so lonely sometimes, feel like I'm going into depression. It's an awful feeling and the biggest thing is having contact with somebody… I'm talking to you and the [personal support worker] that they sent me to, I get a different one all the time…but at least it's somebody to talk to. (P8)

Participants perceived the program as offering a high-touch and holistic approach that contrasted with overly medicalized, truncated, and depersonalized healthcare, including primary and specialty care. A few suggested they preferred the care management over psychiatric services because, as one participant put it:

…to know you are getting this hands-on help that's geared specifically to the person, rather than having to go see a psychiatrist and just have pills administered, that's not solving the problem. (P9)

A family caregiver suggested the term "psychiatry" in the program's name did not reflect what she called this pilot's "whole health approach. (FCG1)

Participants Perceived the Project as Access to Mental Health Care in a Resource-Scarce System

Participants appreciated having their family doctors refer them to the program. The pilot was seen by many as an opportunity to bypass prohibitively expensive private therapy or months spent on a waiting list for mental health services:

Well, just having somebody looking at my physical and psychological moods, you know, that somebody knows exactly what I'm going through, and trying to find a course of action that would help me progress. Having somebody there that, you know, because then it would be so hard to see anybody with regards to mental health. Usually when you call up, it's like three or four-month wait to see somebody. I was fortunate enough to get somebody right away…. (P11)

Access to specialists was a commonly cited reason to enroll in the project. Although two patients were disappointed that they did not receive more intensive talk therapy, all others were content with the indirect access to a psychiatrist. Participants were particularly thankful for the psychiatrist's guidance and monitoring of prescriptions. They perceived there being a great demand amongst seniors in the community for the kind of mental health support the pilot project offered. One participant exited the program before completion once he started to feel better, in order to open enrollment for someone else. A family caregiver pointed out the value of the case review in terms of meeting the perceived demand:

…resources are obviously stretched in every aspect of health care you look at. And to me this was helpful because you, the program allows the outreach to a lot more people than if it was the, each individual seeing a psychiatrist… it's just the best use of resources I thought. (FCG2)

Participants also saw the project as providing resources to supplement the limited access they had to their family physicians:

It was really comforting to know that I could call somebody and discuss whatever was going on, because the family doctor is always busy…I found that very helpful to know that there was somebody there. (FCG3)

Participants Valued Non-Judgmental Support for Meeting Care Goals

Participants identified their participation in collaborative goal setting as an important aspect of the home visits, which was a central component of this intervention. Care managers were perceived as being knowledgeable and resourceful in terms of understanding what participants were experiencing and what they might need. Many emphasized the importance of feeling like the care managers recognized their self-management challenges, supported their efforts, and did not judge their ability or progress, particularly around mental health recovery:

Well, it was very positive. She was very complimentary and supportive and we couldn't say enough about her positivity and helping me set some realistic goals. Not judgmental at all and helping me, you know, setting some realistic goals. (P3)

The same participant suggested "just the warm and fuzzy helps a lot," when talking about how his care manager supported him in forming long-term healthy habits.

Stigmatization (i.e., the social devaluing and isolation of people experiencing decreased physical and/or mental functioning) surfaced here in relation to the value of non-judgmental support. Some participants felt less alone in their illnesses knowing that care managers had worked with other patients going through similar experiences. One family caregiver pointed out how the care manager was helpful in normalizing her husband's experiences with depression:

I think he wanted to know that he wasn't the only one having this problem. And I found that helpful too… it was just helpful to know that this is a problem with lots of people…. (FCG2)

Another participant spoke directly to stigmatization of her mental health issues, which led her to question the use of the term "psychiatry" in the research program's name and literature:

Well, for one thing, the mental health thing is kind of a touchy thing in a way, people don't like that word. You know that. I mean people just don't like that…And mental health, anybody that has any type of problem…anything to do with mental health as they say, everybody makes fun of you. So nobody talks about it and then when you start a program and you call it something to do with mental health, well people don't even want to bother 'cause it's such a taboo, you know? (P2)

Participants Desired a Longer Program and/or Ongoing Contact with Care Managers

Multiple participants—especially those involved for the 6-week duration—thought the project enrollment should be longer and the transition out of the project more tapered. For some, this desire was rooted

in the feeling that their mental health needs were quite complex and required more time to address. One participant described feeling anxious knowing her time with the project was ending:

> I was really disappointed… Because you just get going on something and you really start to feel so much better, and I was terrified that the second to the last visit, I was absolutely terrified that I wouldn't be seeing her again. So, she said to me, well if you're still having problems in several months, you can ask your doctor to see if he can refer you once again. And you know, it feels like, it's a wonderful feeling to have someone out there, helpful and could discuss anything that you need help with. (P9)

A family caregiver also touched on the need for more time in the project for her husband to improve his mental health through such things as physical exercise, eating better, and socializing.

> You know, those aren't things that really can change within a few months. So, if there was a maybe a little checkup process that happened, you know, a few months later, and then a few months later, then six months later, something like that, that might be helpful. (FCG1)

Others shared her wish for intermittent check-ins and continued contact with care managers as a way of transitioning out of the project. The appeal of longer project enrollment can be contextualized within the feelings of security many participants described when discussing what it meant to have direct access to someone if needed:

> …it's comfortable, the fact that you have access, you can pick up the telephone… believe it or not, just the fact that I am now part of this is a great comfort. I think that goes a long way in you maintaining some health and having a normal lifestyle. If I felt "God, why am I, oh, every day I'm getting older, what am I going to do"…and that's all you think about, that there's nobody there for you until you get dragged off to a hospital somewhere, that's not too great. But here you are, you supply something, it's a lifeline I guess, a real tangible lifeline. And I think that has a huge impact mentally. (P1)

DISCUSSION

Overall, participants reported positive experiences with this pilot project and perceived a widespread demand for this kind of community-based intervention amongst seniors in their communities. The discussions revealed participants' perception of their involvement with the pilot as a fortunate opportunity to receive mental health support in a system where such services are otherwise scarce. In addition to timely access to psychiatric expertise, participants valued the project's more holistic approach to integrated care and ongoing, positive support in reaching self-management goals. Multiple participants desired the project to be longer and/or recommended a more tapered transition with ongoing connection to care managers.

The findings highlight the importance of care management within patient perspectives on collaborative care (Taylor et al., 2018). Our participants mainly focused on interactions with their care managers when asked about the program's components and advantages. They valued how managers took time to listen to their concerns and offer skilled, constructive, and non-judgmental guidance on their care planning and self-management. This finding aligns with existing work exploring care attributes important to older people with multi-morbidity and their families, including the desire to have someone compassionate and competent to talk to about their mental health (Grundberg et al., 2014; Grundberg et al., 2016; Kuluski et al., 2019).

The home visits were central to the social connection and emotional support participants felt they received from care managers, as the sessions were experienced as personalized and conversational engagements,

something otherwise rare in contemporary healthcare. Patients' perspectives on the advantages of home visits in primary care have been documented as including the comforts of home, more time with the care provider, higher quality relationship, and a feeling of more personalized attention (Smith-Carrier et al., 2018; Van Kempen et al., 2012). Home visits are particularly valuable for seniors who are homebound due to chronic and co-morbid illness (Wajnberg et al., 2010). This type of one-on-one visit in the home, however, is relatively rare in Canadian healthcare, where this study took place (Chan, 2002). This context presents a challenge for wide-spread implementation of community-based projects, because mechanisms and resourcing for home visits are limited and require supplementary design and funding.

The participants' lament for—and in some cases anxiety about—the project's enrollment length can be contextualized through other research revealing that "feeling cared for" is often a vital benefit of healthcare interventions from the patient's perspective (Webster et al., 2015). Given this reality, future work might explore how and if patient experiences of social and emotional support can be expressly designed into collaborative care interventions in sustainable and scalable ways. This finding further raises the issue of how patients can be supported when care offered through pilot projects is withdrawn and existing systems do not have the capacity to meet patient needs in the same way—as is the case with current primary care models struggling to manage the complexities of multi-morbidity (Ho, Kuluski, & Im, 2017; Upshur & Tracy, 2008).

The project's design required dedicated care manager time for home visits, ongoing communication, and administrative tasks. The weekly structured case reviews also required extensive time and communication between the care team members. Further research is needed to evaluate the project's hub-and-spoke model for capacity-building among community partners to determine how this high-touch clinical working model can scale and spread. Such research is crucial in a fee-for-service system, given that a lack of sustainability due to existing financial and service structure arrangements present barriers to inter-professional collaboration (Knowles et al., 2013; Wood et al., 2017).

It is important to reflect on participants' experience with this collaborative care project and on possible areas of future work in relation to the participants' mention of social isolation and loneliness; these are meaningful dimensions of geriatric mental health and multi-morbidity that are key to consider in relation to the reported desire to feel connected and supported (Berkkman, 2000; Grundberg et al., 2012; Grundberg et al., 2016; Hawton et al., 2011; Nicholson, 2012). Participants also mentioned stigmatization as part of their experience, which patients with multi-morbidity are more likely to experience (Bahm & Forchuck, 2009). Older adults with multiple chronic conditions experience a "double stigma" related to their mental illness and age (Holm, Lyberg, & Severinsson, 2014; Gibbons, 2016; Perrella, McAiney, & Ploeg, 2018). Perceived or internalized stigma can compound the social relevance of stigma and social isolation, particularly amongst elderly patients experiencing mental health issues. Feelings of social exclusion that characterize perceived stigmatization can negatively associate with quality of life, become a barrier to seeking treatment, and predict discontinuation of care in older adults (Connor et al., 2018; Corrigan, 2004; Depla et al., 2005; Rush, Angermeyer, & Corrigan, 2005; Sirey et al., 2001). Stigmatization of mental health in particular is something project teams should be aware of when naming new programs or resources; as was raised in these interviews, the word "psychiatry" was an example of a stigmatizing term that might discourage patient enrollment and/ or continuation of care.

Study Limitations

A limitation to consider is the lack of ethnic and cultural variability amongst the participants. Although some participants mentioned they had immigrated to Canada from European countries, none identified as having backgrounds from non-European countries. Future work should reflect the highly diverse communities within which this project is being carried out to further contextualize patient experiences. The project was also carried out exclusively within a large suburban setting, which could limit the generalizability to rural or other geographic settings where variant professionals and services might be available and/or accessible to patients. The lack of lived experience advisors and/or patient and family caregiver advisors within the research process is also noted as a limitation.

CONCLUSION

Findings from this qualitative evaluation provide insight into patient and family caregiver experiences with a collaborative care pilot project for community-dwelling seniors with multi-morbid conditions, offering key perspectives to inform future design and implementation. These findings concurrently underscore the potential for collaborative care models to provide patient- and family-centred care for seniors in a primary care setting, as well as the urgent need to examine how existing healthcare systems can adapt to meet the rising need for holistic geriatric care in the community. Patient perspectives are vital to the ongoing challenge of designing services to support physical and mental health together.

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