Using Community Engagement to Initiate Conversations About Medication Management and Deprescribing in Primary Care

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Abstract

Polypharmacy, or the simultaneous use of multiple medications, represents a significant public health challenge—particularly among older adults, who are more likely to experience negative clinical outcomes attributable to adverse reactions to or interactions between their medications (Canadian Institute for Health Information, 2013). Improved medication management on the part of both patients and health care providers (HCPs) is needed to address the issues and consequences associated with polypharmacy, but conversations between patients and their HCPs about options for medication changes remain the exception. In a rural community near Ottawa, Ontario, a community-based participatory research (CBPR) approach aimed to support improved public awareness of and participation in medication management and deprescribing through educational events aimed at older adults. This paper describes the processes researchers used in collaboration with community members to discuss and address medication management in a locally relevant manner, details the results of these processes, and suggests how similar approaches may be employed to empower patients and communities to address issues of personal health care.

Our research team has used a rigorous method to develop five deprescribing guidelines intended to help health care providers (HCPs) decide when and how to reduce or stop medications that patients may no longer need or that cause more harm than benefit (Bjerre et al., 2018; Farrell, Black, et al., 2017; Farrell et al., 2016; Farrell, Pottie, et al., 2017; Pottie et al., 2018; Reeve et al., 2018). Although HCPs have widely accepted these guidelines in general, the recommendations remain challenging to implement in practice, and HCPs have told us that they would be more inclined to use them if patients initiated conversations about stopping their medications (Conklin et al., 2019). This is not common, however, so our team set out to work with members of the public to understand how to facilitate these deprescribing discussions.

The Deprescribing Initiatives Using Community Engagement (DICE) project was a co-constructed, community-level initiative to facilitate deprescribing conversations between members of the public and their HCPs. By formalizing a partnership between community members and our research team, we aimed to develop a sustainable strategy within the community, adapt it for broader use, and measure subsequent reach and adoption of the initiative. In this paper, we present our experience developing a local advisory group, summarize advisory group members' perspectives on public knowledge and needs regarding polypharmacy and deprescribing, and outline the resulting educational intervention.

Background

Coexistence of multiple chronic health conditions, or multimorbidity, is common among older adults (Guerra et al., 2019; Salive, 2013). One consequence of multimorbidity is the simultaneous use of multiple medications, a phenomenon known broadly as polypharmacy. Polypharmacy is very common: An estimated two out of three Canadians over the age of 65 take at least five prescription medications, and one out of four takes at least 10 (Canadian Institute for Health Information, 2018).

Although it may be clinically appropriate for an individual to take multiple medications at once, polypharmacy can become problematic when the medications' benefits are negated or outweighed by potential adverse effects (Masnoon et al., 2017). The consequences of such polypharmacy—increased hospitalization and accompanying health care costs; increased risks of falls, drug interactions, and adverse drug events; and increased risk of cognitive decline—represent significant public health challenges (Duerden et al., 2013). Older adults are particularly vulnerable to negative outcomes associated with polypharmacy due both to its incidence among this demographic and to the

physical implications of aging, including changes to the body's ability to metabolize medications. Older adults are hospitalized five times more often than individuals under the age of 65 due to harmful effects from their medications (Canadian Institute for Health Information, 2013).

One solution to the challenge of polypharmacy is deprescribing — a process of tapering, stopping, discontinuing, or withdrawing medications that are harmful or that are no longer having their intended effect. The goal of this process is to mitigate polypharmacy and improve outcomes (Thompson & Farrell, 2013). However, despite HCPs' growing interest in deprescribing and the availability of tools and resources to aid in the process, conversations between patients and their HCPs about deprescribing rarely occur. Turner and Tannenbaum (2017) found that older adults experiencing polypharmacy are often aware that their medications could be harmful to them; nearly half of research participants had independently researched medication-related harm. However, patients largely rely on HCPs to initiate conversations about their medications (Sirois et al., 2017), and clinicians fail to do so on a routine basis (Anderson et al., 2014).

Public awareness of polypharmacy and deprescribing is limited. People who are aware of medication harms and are familiar with the term "deprescribing" are more likely to initiate deprescribing conversations, but older adults remain generally unfamiliar with both the term and the concept (Turner & Tannenbaum, 2017). Approaches to educating the public about polypharmacy and deprescribing are being trialed (Turner et al., 2018) but have yet to be studied in-depth. We are not aware of a community engagement approach being used to develop strategies from the public perspective to support local deprescribing initiatives.

A community engagement approach to social change derives from a growing body of theoretical and empirical work dating back to the 1940s and the early work of Kurt Lewin for the Committee on Food Habits (Lewin, 1943; Wansink, 2002). This work identified the principle that social change is often facilitated when the people whose behavior is expected to change are engaged as participants in the change process. From this theoretical foundation, a plethora of work has emerged on the most effective ways to engage stakeholder populations in efforts to bring about beneficial behavior change (Bunker & Alban, 2006; Bushe & Marshak, 2015), and a variety of community engagement approaches have been found to be effective in positively influencing health behavior and outcomes (O'Mara-Eves et al., 2013).

CBPR is a community engagement approach to public health research that centers local needs, interests, and experiences to improve the adoption and sustainability of intervention activities (Israel et al., 2013). There is increased recognition that community engagement is a crucial determinant of success in public health initiatives (Gebbie et al., 2003; National Institute for Health and Care Excellence, 2016). Depending on its depth and nature, community involvement can facilitate capacity development (Mason et al., 2013) and community empowerment (Martin, 2008). It also improves the relevance of local-level interventions (Balazs & Morello-Frosch, 2013; Norman et al., 2013) and supports increased quality and validity of research without sacrificing rigor or reliability (Balazs & Morello-Frosch, 2013). When approached thoughtfully, CBPR benefits both communities and researchers, facilitating a bidirectional flow of information, skills, and resources while actively addressing issues of equity, access, and decision-making power (Balazs & Morello-Frosch, 2013; Buchanan et al., 2007). The goal of maximizing community engagement in research and intervention processes anchors the core principles of CBPR and presents unique and complex challenges. Considering evidence that public awareness may be a key element in meaningfully addressing issues of polypharmacy and deprescribing (Turner et al., 2018; Turner & Tannenbaum, 2017; Working Group on Medication Overload, 2020), CBPR has promise as a powerful and practical mechanism for encouraging the public's interest in and engagement with these topics.

Research Team Characteristics

The research team consisted of four coinvestigators, three of whom have health care backgrounds in pharmacy (PharmD) and have actively supported patients in deprescribing efforts. The fourth is a social scientist (PhD) with a background in organizational culture change. All are scientists associated with different Canadian research institutes. This team has worked together since 2013 on the project to develop and implement deprescribing guidelines. A social science research associate (MA) with experience in community engagement and qualitative methods interacted with community members to develop a local advisory group and to manage all data

collection and analysis. This person is not an HCP and had no experience managing polypharmacy or deprescribing. The research team also hired a practicing pharmacist (BScPhm) to facilitate group discussions about polypharmacy and deprescribing. Five team members are women; the social scientist is a man.

Methods

Formation of the Local Advisory Group

The research team scheduled and advertised an initial public meeting in a small, primarily English-speaking community (approximate population 2,400, with 30% over the age of 65 and an average age of 46) to solicit interest in the project and to begin the formation of the local advisory group, or "LAG." However, our lack of local knowledge early on resulted in the selection of an event venue that, as we later learned, was not much used by the community and was not easily accessible to older residents due to its distance from downtown. This event was poorly attended, but it did put us in touch with a journalist from the local newspaper. We were able to use this contact later to advertise both the project and the final event to the community.

Using publicly available information, we reached out to local residents identified through their existing engagement in community organizations and activities, such as local social clubs and service organizations. We anticipated that these individuals would likely have established relationship networks in the community, making them not only valuable research participants but also potential entry points for the research team into the greater community. We conducted initial outreach by email and followed up by telephone, resulting in meetings with two local organizations. We also employed opportunistic and snowball recruitment methods, soliciting and following up on recommendations from well-connected residents.

Ultimately, five local women joined the LAG: Three were between the ages of 55 and 74 and two were in their 80s. Two women had nursing backgrounds (one was employed as a community wellness nurse and the other was retired), two worked with a senior services provider (not health care related) in the community, and one represented a provincial seniors' advocacy organization and was a caregiver for her spouse. All had lived in the community for at least 10 years, some for over 30 years. The group met regularly over the winter and spring of 2018–2019 at a community boardroom and received no financial compensation for their participation. Data collection was approved by the research ethics boards of the Bruyère Research Institute, the University of Toronto, and Concordia University. All members of the advisory group were informed of the project's parameters and goals and participated voluntarily. All members signed prepared project information forms indicating their informed consent to participate. The process is outlined in Figure 1.

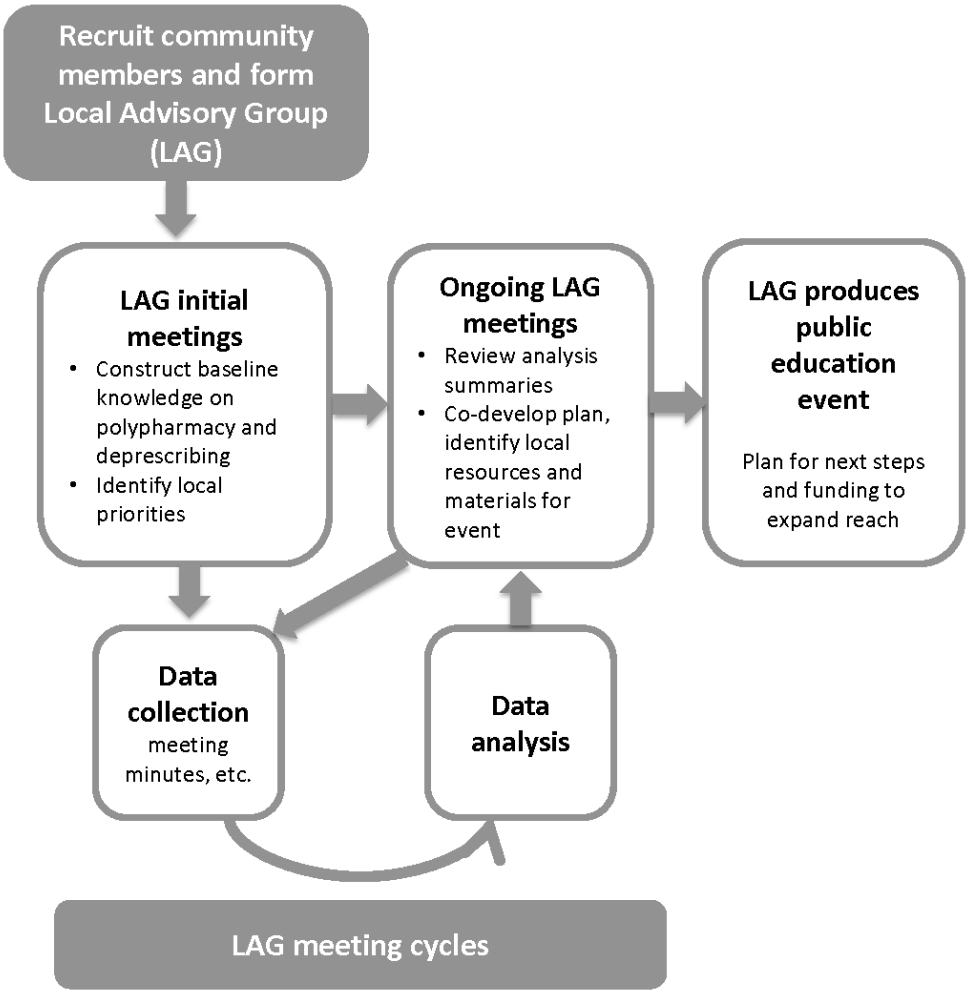
Local Advisory Group Process

In designing, forming, and facilitating the LAG, our central challenges were (a) operationalizing the key principles of CBPR and (b) maximizing engagement. The process needed to prioritize the voices and experiences of the community and minimize the degree to which researcher biases might dampen or negate the LAG's perspectives. While we possessed a "big picture" idea of the issues surrounding deprescribing, our goal was to discover how patients and HCPs experienced these issues on a personal level. Toward this end, we took a conversational, open-ended approach. At the same time, the LAG space needed to foster trust between members of the community and the research team, facilitate cocreation and shared decision-making, and support a multidirectional flow of information.

We used a multimethod qualitative approach focusing on descriptive validity and minimal inference. Approaching participation as a dynamic process (Draper et al., 2010; Stauffacher et al., 2008; Tritter & McCallum, 2006), we employed an evolving mix of complementary methods to structure discussions, facilitate consensus on actionable priorities, and guide intervention creation. The objectives, activities, and outcomes of each advisory group meeting are summarized in Table 1.

Articulating Key Issues. The advisory group's initial meetings had two goals: (a) to establish a bidirectional flow of information between community members and the research team and (b) to establish a common understanding of the issues of polypharmacy and deprescribing from a local perspective. The High Plains Research Network's Boot Camp Translation (BCT) model suggested a practical framework for creating a shared knowledge base among community members and researchers (Norman et al., 2013). Developed at the University of Colorado, the BCT model is a process for translating evidence-based best practices in health prevention and chronic

Figure 1. Local Advisory Group process



illness care into accessible public health messaging that emphasizes patient-driven change and self-management (Fagnan et al., 2018). It has been used to create successful campaigns addressing colon cancer screening, routine asthma care, and hypertension monitoring (Norman et al., 2013).

The LAG's first meeting began with an overview of polypharmacy, deprescribing, and the research process via a PowerPoint slideshow. During the presentation, members were encouraged to ask questions, request clarifications, and share thoughts about the content. The goal of this informal approach, drawn from the BCT process, was to foster group cohesion and to establish a participatory norm early on. The group then engaged in silent generation of responses to and thoughts on the information covered, using question prompts on a worksheet prepared by the research team as a starting point. Next, a roundtable discussion focused on perceived local issues surrounding polypharmacy and medication use, particularly among older community members. Borrowing from Van de Ven and Delbecq's (1972) nominal group theory, we chose this process for its capacity to highlight points of consensus and divergence among group members and to balance contributions from assertive and more reticent participants. The group's first meeting also allowed LAG members to get a clearer understanding of the LAG's purpose and goals, the formal research process that would guide the group's activities, and the implications of working within such a process (e.g., the requirements of the research team's institutional research ethics board and the necessity of accurate and thorough documentation of data).

One research associate (acting as facilitator) and one team pharmacist (cofacilitator and content advisor) participated in the initial meetings. This minimal representation was deliberate, reflecting

Table 1. Local Advisory Group Meetings Objectives, Activities, and Outcomes

Meeting	Objectives and Activities	Outcomes
December 2018	Objectives: • Establish bi-directional flow of information between community members and research team • Establish a common understanding of polypharmacy and deprescribing Activities: • Research team presentation of LAG purpose, polypharmacy, deprescribing, and research process; LAG encouraged to ask questions and share thoughts during presentation • LAG silent generation of ideas using a worksheet with question prompts • Round-table discussion of local issues relating to polypharmacy and medication use	Many older adults don't know: • what medications they're on and why • that some medications affect older adults differently • where to go for information and advice or what questions to ask • that they have the right to ask questions about their medications Older adults: • experience information overload • may not have the physical or mental capacity to ask questions (e.g. frailty, cognitive decline, in residential care, residing in remote locations) Doctors: • are seen by many older adults as authority figures not to be questioned • are trusted to make the 'right' decisions for their patients • may not inform patients they can ask questions or give them the chance to do so • don't always have time for in-depth conversations; appointments are short Other observations: • Older doctors more likely than younger to prescribe • Worry that prior diagnoses will affect concerns being taken seriously • Meds may be free or low-cost; less reason to question their necessity

February 2019	Objectives:
	• Translate problems into priorities that can be targeted by intervention
	• Introduce concepts of behavioral change
	• Prioritize 'target behaviors,' articulate 'outcome behaviors,' and discuss what is needed to bridge the two (basis of intervention)
	Activities:
	• Review of key points from last meeting
	• Overview of existing deprescribing research
	• Completion of individual worksheets and guided discussion to reach consensus
	  • What is the problem we are trying to solve?
	  • What is the behavior we are trying to change?
	  • In what way are we trying to change this behavior?
	  • What will it take to bring about this change in behavior?
		People need:
		• information about polypharmacy and deprescribing
		• information about their current medications and options
		• appropriate amounts of relevant information, presented in approachable language and format, and strategies to access that information
		• tools to facilitate self-advocacy
		• mechanisms of assurance and support to address fears and concerns
		Healthcare providers (HCPs) need:
		• information about polypharmacy and deprescribing
		• guidelines and decision-guides to support them in having conversations about medication issues
		• language and skills to effectively and clearly address patient concerns support in the processes of medication evaluation and deprescribing
		Target behavior:
		• Older adults and their HCPs are not having meaningful conversations with each other about medication management, inhibiting shared decision-making and patient engagement
		Outcome behavior:
		• Older adults and their HCPs initiating and sustaining open, informed, mutually-satisfactory conversations about polypharmacy and medication management

Table 1 (continued)**.** Local Advisory Group Meetings Objectives, Activities, and Outcomes

Meeting	Objectives and Activities	Outcomes
March 2019	Objectives: • Learn about and discuss locally-available healthcare resources and community assets • Brainstorm intervention Activities: • Powerpoint presentation on polypharmacy and deprescribing tools available for the public and healthcare providers • Discussion of community assets • Discussion of needs the LAG can address and specifics to consider for an intervention	Most of the issues discussed center around communication in the "circle of care" : • Older adults don't see themselves as part of the circle of care • Those who are interested in talking to their HCPs don't know how/where to start Potential interventions need to: • Take place in-person • Be relatable (language, experience) • Place the patient/client (back) into the circle of care • Blend education and support/enablement strategies • Emerging strategy: a series of interactive public sessions • Start with basic concepts ("circle of care," patient rights) • each session builds on what was learned, discussed in the last session • progress to more difficult concepts and questions (polypharmacy, deprescribing)
May 2019	Objectives: • Determine goal of the education session • Identify who should be invited • Determine how the message will be delivered • Determine logistics of the session (where, when, what, how, who) Activities: • Review funding change • Review LAG discussion summary to date • Discussion of operationalizing LAG-led community education initiative	A single public education event involving: • A member of the public, pharmacist, and a physician from the community to speak about why and how older adults can start talking to their healthcare providers about their medications • A panel made up of the above to answer audience questions • Local healthcare providers to talk with attendees during an informal 'mingle' following the more structured part of the event • General and event-specific take-home materials for attendees • A 'commitment' mechanism to support attendees in following up on their learnings

the research team's concern with giving the nascent advisory group space to build internal relationships and capacity without the potentially overwhelming influence of formal expertise. Over time, additional research team members and local HCPs also came to attend advisory group meetings.

The advisory group met four times over six months, with each meeting's agenda determined by the decisions made and priorities set at the previous meeting. These meetings were supplemented with occasional, smaller meetings to welcome new members and to allow existing members to catch up on and contribute to the content of any missed meetings. Participants and researchers were encouraged to complete post-meeting memos to track new and emergent understandings, to explore and react to issues and ideas that came up during meetings, and to assess the perceived effectiveness of the research process (i.e., Did participants feel the process was accomplishing what they hoped or understood that it would?; Birks et al., 2008).

Data Collection and Analysis. Shortly following each meeting, three members of the research team received a data package consisting of meeting minutes, researcher and participant memos, field notes, and other meeting materials (such as slides, handouts, and worksheets). Team members analyzed these packets using developmental evaluation—a utilization-focused process aimed at generating rapid, "real-time" feedback to inform and support the proceeding phase of intervention development (Rey et al., 2014). Using a rapid analysis technique premised on a common, structured template, each analyst produced a memo highlighting patterns in the data and any insights that emerged during review. The entire research team reviewed these memos and noted patterns and implications in the analyses before meeting to reach consensus on "lessons learned." The resulting summary was presented to the advisory group at the start of the next meeting for discussion and endorsement or repudiation (it was also sent to absent advisory group members to include them in the process). Team members proposed themes based on recurring topics and relationships around which the memoed data appeared to cluster, and these were checked against the data to confirm coherence, relevance, and depth (Braun & Clarke, 2006).

Focusing on Behaviors. The results of the first meeting were a set of issues, concerns, and ideas which described what the LAG perceived to be key drivers of polypharmacy and barriers to deprescribing in their community. To translate these items into actionable priorities for intervention, the research team employed the COM-B model, the foundational component of the Behavior Change Wheel (BCW) framework (Michie et al., 2011). This model facilitates the selection of effective intervention strategies by identifying target and outcome behaviors and the relationships between the two. It has been used to develop a range of health care interventions addressing such goals as medication management in multimorbidity (Sinnott et al., 2015), dietary behavior change (McEvoy et al., 2018), and medication adherence (Murphy et al., 2014).

The LAG focused on answering four core questions:

1. What is the problem we are trying to solve?
2. What is the behavior we're trying to change?
3. In what way are we trying to change this behavior?
4. What will it take to bring about this change in behavior?

By identifying target behaviors as well as drivers and deterrents using the COM-B model and BCW framework, the advisory group articulated the focus and goal of the intervention (discussed below). Next, group members conducted a community assets inventory (Sharpe et al., 2000), applying their experiential knowledge to recommend strategies and local resources for implementing the anticipated intervention. The inventory included consideration of accessible public spaces in the community, local opportunities for event promotion and advertising, and known, trusted local HCPs who might act as both promoters of and participants in the eventual intervention.

Results

Here, we describe four themes that emerged from the research team's analysis of advisory group discussions, an outline of the group's planned intervention, and the group's ultimate actions.

1. Older People Have Access to Very Little Understandable Information About Their Medications

LAG members expressed concern that many people, particularly older adults, are taking too many medications without necessarily knowing what they are for, why they are taking them, what effects to expect from them, or how the effects of certain medications may change with age. Older adults can be overwhelmed by the volume of medication information they receive, particularly if it comes in the form of generic, pharmacy-

supplied, medication-specific pamphlets or if content is written in complex, technical language. Confusion can arise when a medication brand is changed, unfamiliar generic names are used, or new options and alternative treatments are proposed without explanation of the benefits and risks. Although accessible information about medications is important, LAG members also felt that the skills people need to acquire that information are equally important, particularly in terms of how to ask HCPs questions about medications. Patients may not be motivated to ask such questions depending on how they perceive the authority of the prescriber and their own role in medical decision-making.

2. Older People Fear Asking Their Physicians Questions About Their Medications

According to LAG members, older adults believe HCPs may perceive them as questioning a doctor's decisions or as "difficult" patients if they ask questions about their medications, which they fear could result in denial of care, loss of access to treatment, or dismissal from their physician's practice. LAG members described people's feelings of intimidation as well as fears associated with having their concerns dismissed, experiencing consequences of new treatment plans, and changing established patterns of behavior. Advisory group members believed that these fears may stem in part from a power imbalance between people and physicians, wherein patients perceive physicians as authorities on medications and treatment, believe that medical decisions are the purview of physicians, and trust physicians to make the right decisions. Some older people feel their physicians are uninterested in concerns and questions about medications or treatment plans or they don't have time to address them. Group members also had a sense that people might be more comfortable asking pharmacists questions but did not necessarily do so out of concern about imposing on them when they appear busy.

3. Older Adults Are Unfamiliar With the Concept of the "Circle of Care" and Therefore Do Not Recognize Their Role Within It

In recounting how older people engage in their own health care, LAG members described a marked level of passivity. They described many as unaware of their rights to receive a full and accurate account of their health status from their physician, to be consulted, to ask questions, to share their goals and preferences, and to participate in their health care decisions. As a result, they felt patients often failed to engage in their own health care due to a lack of interest or capacity. These observations suggest that older people may not conceive of a "circle of care" in which HCPs partner with them to provide care that aligns with their needs and goals. The circle of care typically refers to the "ability of certain health information custodians to assume an individual's implied consent to collect, use or disclose personal health information for the purpose of providing health care" (Information and Privacy Commissioner of Ontario, 2015). The advisory group started to apply the term to collectively describe individuals involved in managing a person's medication and treatment plan (including the person themselves). The circle of care framework conceives the patient not as a passive recipient of care at the center of the circle but as an active part of the circle. The LAG suggested that older people often do not see themselves as health decision-makers and rarely engage in self-advocacy for their care, as this simply does not occur to them.

4. Relationships Among HCPs and With Their Patients Are Not Always Present or Effective

LAG members suggested that relationships between older people and their HCPs within the circle of care are failing to achieve optimal medication management. Local pharmacists attending the LAG meetings confirmed that hospital and community pharmacists rarely communicated during transitions in care, leaving the latter lacking information about medication changes made in hospital. Even in this small community, the hospital and community pharmacists attending the meetings did not know each other. Communication between community pharmacists and physicians relies heavily on fax transmissions that frequently go unacknowledged. LAG members also perceived that many older patients' deferential attitudes toward their doctors reduced the effectiveness of the physician–patient relationship, and they pointed out the difficulty for isolated older people and those living in long-term care to maintain relationships with their HCPs that would allow detailed discussions of medications.

Summary

Together, the four themes reveal a pattern of interaction and communication within the community that impedes deprescribing medications for older adults. Control and authority over medication decisions is ceded

to physicians instead of being the shared responsibility of patients, physicians, and pharmacists. Patients receive information about medications that, although valid and useful, is presented in a complex manner that is difficult for patients to understand—if it is presented at all. Disconnections in communication among HCPs make it challenging to maintain an accurate and complete record of a patient's medications, and it is often unclear whether important information has been received and considered. Questions and concerns are suppressed, and collaborative decision-making within the circle of care rarely takes place. These themes informed the LAG's next steps.

The LAG's Initial Plan

Group members determined that an intervention should empower older adults to initiate conversations with their HCPs and participate more actively in medication-related decisions. They proposed a series of local educational events for older adults, with the first designed to help attendees develop a basic understanding of their role as patients in managing their medications. Each event would build on previous events to improve medication literacy, culminating with the concept of engaging in shared decision-making. The gradual introduction of basic then more complex information and skills was proposed to maximize support among community members and improve retention of information. The LAG suggested involving local experts (pharmacists, physicians, public) in these events to help attendees build confidence and competence through discussion and role playing. The group also conceived a component in which attendees would create a written commitment to action based on their learnings. To coordinate relationship building and communication among HCPs, the group planned a concurrent information-sharing strategy.

What the Group Carried Out

As the advisory group began planning the proposed education series, all Health Service Research Fund grants were discontinued by the Ontario provincial government, and research teams were told to wind down activities over a 90-day period. The group determined that a

Table 2. "Talking About Your Medications" Public Event Outline and Description

Event Part	People Involved	Description and Purpose
I: Members and Roles in the Circle of Care	Speakers: • Local resident • Local community pharmacist • Hospital physician	• Short (5-10 minute) talks from individuals representing different members of the circle of care • Establish baseline knowledge about the members and their roles in medication management • Get attendees thinking about potential concerns or questions they might want to ask later in the session • Speakers use personal experience and local relationships to connect with attendees
II: Panel Questions Period	Speakers, MC from local partner organization	• Attendees submit written questions to be drawn at random and read out-load by host • Allow attendees the opportunity to share experiences and ask questions that are relevant to them • Format allows for anonymity, balances the contributions of more and less confident participants
III: Mingling Period	Attendees, speakers, local healthcare providers	• Following formal portion of meeting, attendees and local HCPs invited to partake in refreshments, mingle with each other • Encourage attendees to make one-on-one connections with speakers, healthcare providers and ask more questions

single, abridged public event would honor their commitment to community members and would provide the community with tools to continue an intervention after the departure of the research team. Individual group members took on responsibilities in organizing and advertising the event, recruiting local speakers, and managing the event itself.

The 2-hour evening event, "Talking About Your Medications," was conducted in partnership with the local senior center. It focused on encouraging people to initiate conversations with their HCPs about their medications by demonstrating the patient's role in the circle of care. The session was presented in three distinct parts (see Table 2).

To initiate and sustain behavioral change, LAG members felt attendees needed a take-home information resource and a way to commit to an action plan. Together with the research team, the group produced two resources: a trifold handout (Appendix 1) and a "My Appointment Plan" template (Appendix 2). The local senior center and a local pharmacy agreed to continue supplying these to community members after the event.

LAG members were pleased with the turnout. A local resident, a local community pharmacist, and a physician from a nearby urban area participated on the panel. In attendance were 33 community members (primarily seniors) along with a local hospital pharmacist, two pharmacy students, and four members of the research team. A short, written survey was distributed to attendees to gather informal feedback about the event. Attendees universally approved of the event's format and content, and they expressed particular satisfaction with the question period and the opportunity to have informal conversations with the HCPs present. In addition, a public event planning guide was made available on the research team's website (https://deprescribing.org/public-event-planning-guide/) to support other communities in holding their own medication management events.

Discussion

By engaging with community members, we were able to contextualize polypharmacy, deprescribing, and medication management in a locally relevant way. Many of the LAG members' experiences and observations confirmed concerns and issues described in the literature about older adults' views on and experiences with medication-related decision-making (Belcher et al., 2006; Modig et al., 2012). Their impression that authority over medication decisions is often ceded to physicians, instead of being perceived as a shared responsibility, is consistent with Belcher's findings that many older people do not want to participate or have difficulty participating in health-related decisions (Belcher et al., 2006; Modig et al., 2012). Research has also described the potential obstacles to participation raised by the LAG members, including the fear of being categorized as "difficult" and the desire to conform to the socially acceptable role of a passive recipient of health care. The group also contended that HCPs present information about medications in a manner that is difficult for people to understand—or in some cases not at all—leaving many older adults unable to meaningfully participate in decision-making even if they would like to do so. Others have called for better medication information, including standards and oversight to address this issue (Shrank & Avorn, 2007).

The LAG's perception of physicians' authoritarian attitudes may or may not be correct, but the perception itself signifies a barrier to collaboration. The group also identified a new perspective that has not been described in the literature: The lack of accurate and complete records of patients' medications complicates the potential for older adults to participate in shared decision-making with their HCPs and deserves further study.

The CBPR approach allowed researchers to access local knowledge and experiences and increased both the rigor and relevance of the research findings beyond what a hierarchical, researcher-led process could have produced (Balazs & Morello-Frosch, 2013). That LAG members identified local issues confirmed by other research findings lent support to researchers' confidence and drive that they were indeed addressing widely known but locally relevant issues. There were some initial concerns regarding the extent to which LAG members meaningfully reflected the community on whose behalf they were speaking. For example, all members of the LAG were older women who had experience working in health care and/or with organizations for older adults. However, all members were also long-term residents of the community and had experience with their own medications, in caring for older people with medication concerns, or both, putting them in a strong position to guide the LAG's work. Further, as Steuart (1993) discusses, CBPR participants often differ from members of the community at large, particularly in regard to education and income, as these individuals are often in a better position to

participate in research while also providing an insider's view of community life (Steuart, 1993). In short, professional experience should not negate participants' status as members of the community and may in fact enhance their capacity to inform a given study (Israel et al., 2008).

The LAG's local knowledge was key in the logistical planning of intervention activities. Early in the process, the research team planned and held a poorly attended public LAG recruitment event in the early afternoon at the local community center. The LAG later informed the team that the time and location of the event had been inconvenient to its target audience and that researchers had employed the venue's official, but uncommonly used, name in event advertising. The LAG was able to apply its members' knowledge of local preferences and habits both to plan their educational event at a time and place that would maximize the target audience's attendance and to design and distribute advertising that would effectively reach it.

As the LAG began strategizing about how it would address its core issues, the emerging strategy mirrored the group's own process. LAG members entered the study with significant knowledge, both experiential and professional, about polypharmacy issues among older adults in their community. However, they demonstrated minimal conceptual and extra-local knowledge on the subject and awareness of existing initiatives and resources. The research team's provision of this information helped group members contextualize their knowledge and experiences, supporting realistic and appropriate intervention planning.

Early in the group's work, the research team took the lead in defining and organizing the group; the concern at this stage was that researchers' influence and biases would undermine the stated goal of community-centered prioritization (Ross et al., 2010). As the group's understanding of process increased, so too did members' ability to bring their knowledge and experiences to bear, increasing the group's capacity to address perceived community needs and priorities (D'Alonzo, 2010). Clear leaders emerged in the group, and ownership of both process and outcome increased, reflecting a fluid, situation-specific, and participant-directed model of community participation (Tritter & McCallum, 2006) in which each component of the engagement process demands an evolving profile of collaboration. This is in contrast to the linear, siloed conceptualization of community participation represented most famously by Arnstein's ladder, which has been challenged as oversimplified, inflexible, and power-centric (Morgan, 2001). This outcome suggests that once a community engagement process is underway, a LAG may be able to take on progressively more independence and initiative, particularly if a clearer, self-defined structure and process emerges.

Several emergent factors compelled us to adopt a more flexible group structure and process than we had first envisioned. Originally planned as a group of around half a dozen members who would commit to the project from beginning to end, a dragging recruitment process compelled us to create a rolling form of member recruitment that would allow new members to join the LAG after the initial group was established. This involved "onboarding" new members so they could join the existing group with similar baseline knowledge and a clear sense of the group's progress. Onboarding was accomplished via one-on-one, in-person meetings with new members using revised introductory materials and summarizing the issues and decisions that had emerged from the LAG until that point. New members also had the opportunity to endorse, reject, or otherwise contribute feedback to the processes that had occurred prior to their joining.

An unusually snowy and icy winter forced the group to rebook its second meeting three times, prompting concerns about continuity and maintaining group member buy-in. Early communication issues aggravated this delay: At its first meeting, the LAG agreed that communication among the group would occur by email, but LAG members did not consistently or reliably respond to emails. The research team adapted by reducing the number of emails sent, minimizing the information remaining emails contained, and restricting decision-making to in-person meetings. LAG members responded positively to these changes.

Group members often had conflicting schedules, making consistent meeting attendance by all members challenging and prompting concerns that inconsistent attendance would lead to a disconnected process and data biased toward a subset of the group. To avoid this, absent group members' input was solicited via email, phone, and smaller group meetings and recorded in minutes and researcher memos. The research team also adapted how meetings themselves were organized, introducing a high level of flexibility in order to work for both small groups and larger discussions.

Implications and Conclusion

Our findings have implications for members of the public and for HCPs. People need to know more about their medications, they need skills to help them find that information, and they need to be comfortable approaching their HCPs with questions. They and their HCPs need to see the patient as part of a "circle of care," with a joint responsibility for information sharing and decision-making. Building these skills and shifting how people see their relationship to their medical care is not likely to happen with a single intervention; thus the recommendation to build skills gradually over a series of interactive educational events seems important. Those developing and delivering education or support to individuals need to keep in mind that transitioning people to take a central, informed, and accountable role in their own health care will often take time and sustained effort. In this context, the LAG emphasized the importance of getting participants started with a basic understanding, gradually building knowledge and new skills, and allowing opportunities for practice. In the public forum offered by our workshop, participants were able to interact safely with HCPs and encouraged to ask questions; through these interactions, they acquired new knowledge and skills in a nonthreatening forum that mitigated their worries about talking directly to their physician about their own medications.

Additionally, our community partners' knowledge of medications and polypharmacy was consistent with what we found in the literature. However, the engagement process allowed us to discover an additional salient point: The lack of accurate and complete records of a patient's medication use may hamper the patient's ability to participate in shared decision-making. This deserves further study.

Since the completion of this study, the Lown Institute has released a National Action Plan to eliminate "medication overload," which they define as "the use of multiple medications that pose a greater risk of harm than benefit" (Working Group on Medication Overload, 2020, p. 7). Their recommendations include raising awareness about medication overload, implementing prescription checkups, and improving information at the point of care—all key components of the LAG's discussions and proposed solutions. Our findings support the potential for collaboration between researchers and communities in creating and implementing public health interventions to address the concerns and recommendations outlined in this action plan. Local knowledge not only allowed for the integration of local concerns and interests in the prioritization of key issues but also allowed the intervention events themselves to be better attuned to local habits and preferences. Over the course of the process, LAG members took on greater leadership and planning roles, indicating increased group capacity and confidence—crucial components in the sustainability of public health intervention planning. Additionally, the group's echoing and contextualization of known issues and concerns affirmed the importance of addressing polypharmacy and medication management in the context of community-level and community-led public health interventions.

Finally, our experience has allowed us to identify some "lessons learned" that may be useful for other groups approaching this kind of collaborative and community-based work. Overall, we learned that CBPR was an effective strategy to engage with members of our stakeholder community. The resulting shared decision-making approach ultimately enhanced our team's knowledge of local habits and helped us identify the best opportunities and recruitment strategies to engage effectively with the community's wider public audience. Community members' participation in the CBPR process appeared to encourage them to view our codesigned process and its intended outcomes as their own. This sense of personal ownership and commitment is likely to be important for researchers who are hoping to maximize the reach, adoption, and implementation of their work.

We learned that researchers working with a CBPR process need to be flexible and adaptable for community members. For example, flexibility in how community members could participate in the process was key to maintaining the interest of our LAG members and respecting their boundaries regarding availability and communication. We occasionally found it necessary to schedule separate "catch-up" meetings for members who missed meetings and reduced the research team's reliance on email as a main form of communication. We also found it necessary to accommodate a rolling recruitment process as new members joined and to modify our communication and meeting processes to suit individual and community needs. Localized knowledge of community habits and preferences was as valuable as insights into local issues and concerns and allowed us to cocreate both an appropriate communication strategy and an event plan that maximized potential participation.

Lastly, rather than "one-off" events that do not support the building of new habits over a longer time period, a progressive, "scaffolded" approach may be more effective and accessible to build knowledge and capacity among both advisory group members and community members.

While we were unable to apply some of these lessons outside the LAG process due to loss of funding, new project funding (acquired after the closing of the DICE project) will not only allow for intervention activities to be planned and conducted as the advisory group originally envisioned but will allow the research team to evaluate the outcomes of the intervention, providing a clearer picture of reach, effectiveness, and impact.

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Appendix 1. "Talking About Your Medications" Tri-fold Handout (back)

WHAT QUESTIONS SHOULD I ASK?

Whether you're starting a new medication or have had the same prescription for years, it's important to make sure you and your healthcare provider understand each other. Here are some questions you can ask your doctor or pharmacist.

- What is the name of this medication and what is it for?
- When should I take this medication and how much should I take?
- How will I know if this medication is working the way it should?
- What side-effects should I look out for?
- What should I do if I have side-effects?
- Can this medication interact with any of the others I already take?
- How long should I take this medication? When should it be reviewed?
- Am I taking any medications I no longer need? Can I stop or reduce the dose of this medication?

Always speak to your doctor, pharmacist, or nurse before changing or stopping any medication.

For more information visit the Bruyère Deprescribing Research Team at www.deprescribing.org

HOW SHOULD I PREPARE FOR A CONVERSATION WITH MY DOCTOR OR PHARMACIST?

There are some steps you can take to make it easier to talk to your health-care provider about your medications.

Being prepared can help both you and your healthcare provider feel more confident about your medications.

- Always have an up-to-date list of your medications, including when you start new medications, when your dose changes, and when you stop taking something. Bring this list to your appointment.
- Include any over-the-counter medications like Tylenol, as well as any vitamins or supplements you take.
- Make an appointment just to talk about any concerns or questions you have.
- Before your appointment, write down your questions; this way, you won't have to worry about missing something important.
- Bring a notepad to your appointment so you can write down the answers to your questions. If you have trouble writing, bring someone you trust to your appointment (a spouse, friend, PSW) so they can take notes for you.

YOUR HEALTHCARE PROVIDER NEEDS YOUR HELP TO MAKE THE BEST DECISIONS ABOUT YOUR MEDICATIONS.

Your circle of care is made up of you and the healthcare practitioners—like your family doctor and your pharmacist—who work together to make sure you are getting the medical care that best suits your needs and goals. This includes finding the right prescription medications for you.

Your role in the circle of care is just as important when it comes to decisions about your medications. In fact, all the members of the circle of care are experts with their own contribution to make.

YOUR PHARMACIST

Your pharmacist is a medication expert. They are highly trained and knowledgeable about safe and effective medication use. They can:

- Counsel you on how to use your medications and help you feel confident about taking them
- Answer your questions and address your concerns about new and existing prescriptions
- Monitor and review your prescriptions to make sure they're working the way they should
- Talk with your doctor to start, adjust, or stop medications as your needs change
- Offer non-drug options to help manage symptoms
- Identify potential side-effects or interactions

YOUR CIRCLE OF CARE FOR MEDICATION MANAGEMENT

Some other experts that might be part of your circle of care can also answer your questions about your medications. These include nurses and nurse practitioners as well as any specialists you see, such as the doctors who help take care of your heart health, diabetes, or other chronic condition.

YOUR DOCTOR

Your doctor is an expert in medical care. They use their expertise and your input to find the best treatments for your needs. They can:

- Answer your questions about your medications and possible alternatives
- Discuss issues you may be having with your current medications
- Work with you to determine your health goals and how to achieve them
- Help you feel comfortable and confident about discussing your medications

AND YOU!

You are an expert on your needs, goals, and how your medications make you feel. By providing your healthcare providers with the best information you can, you're contributing to your health and quality of life. You can:

- Come to your appointments prepared with your questions and concerns
- Provide your doctor and pharmacist with the most accurate information possible about your health and medication history
- Ask questions about things you don't understand or need more information about
- Inform your healthcare provider of your goals and preferences regarding your medications; you might have something different in mind than they do
- Let your doctor or pharmacist know if you have concerns or are having trouble with your medications.

Appendix 1. "Talking About Your Medications" Tri-fold Handout (inside)

Appendix 2. My Appointment Plan Template

My Appointment Plan

I have made an appointment with my **doctor or pharmacist** (circle which one) to talk about my medications.

My appointment is with _____

on _____(date) **at** _____ AM/PM

Three questions or concerns I would like to talk about are:

1._____

_____

2. _____

_____

3. _____

_____

I will bring to my appointment:

□ A written list of all my current medications, including over-the-counter pills, vitamins, and natural health products

□ My list of questions, concerns, and information I want to talk about

□ A notebook and pen to write down what I learn

□ Someone to take notes for me if I have trouble taking them myself