

Using Shared Decision-Making Resources in Long-Term Care: a Qualitative Study



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<https://doi.org/10.5770/cgj.26.657>

ABSTRACT

Background

Shared decision-making (SDM) incorporates people's individual preferences and context into individualized, person-centred decisions. Persons living in long-term care (LTC) should only take medications that are a good fit for them as individuals.

Methods

We conducted a pilot study to understand experiences of two LTC homes in Ontario as they tested implementing SDM resources to support medication decisions. LTC homes conducted two Plan-Do-Study-Act (PDSA) cycles supported by an Advisory Group composed of LTC home representatives and stakeholders involved in resource design. Rapid qualitative analysis of transcripts and field notes from Advisory Group meetings elucidated how SDM resources were used.

Results

Each site was positively engaged but implemented resources differently. The pharmacist and physicians at Site 1 introduced proton-pump inhibitor (PPI) deprescribing as their primary intervention, identifying suitable residents, informing residents and families of the deprescribing process, and providing selected SDM resources to residents, caregivers and staff. Representatives reported limited engagement with SDM resources and difficulty measuring the impact of PPI deprescribing. Representatives from Site 2 disseminated the SDM resources to residents and caregivers for use at care conferences and focused on front-line staff education and involvement. This site reported that some residents/caregivers were interested in participating in SDM and using the resources, while others were not. The impact of the resources on SDM at this site was unclear.

Conclusions

Within the context of LTC, further research is needed to clarify the meaning and importance of SDM in medication decision-making. Implementation of SDM will likely require a multi-faceted approach.

Key words: shared decision-making, deprescribing, older adults, medication management, resource implementation

INTRODUCTION

Shared decision-making (SDM) in long-term care (LTC) involves both the resident (and/or caregiver) and health-care providers achieving a common understanding of available options, the pros and cons of each option, and resident treatment preferences.⁽¹⁾ SDM is a strategy that can be used to ensure every medication a resident takes is necessary, effective, safe, and consistent with their health-care goals and treatment preferences.⁽²⁾ Many LTC residents take at least some medications which do not meet these criteria.^(1,3,4) Qualitative studies have demonstrated potential for improvement in SDM in LTC⁽⁵⁾ including in the context of medication use.⁽⁶⁾ While residents may have different levels of willingness to participate in medication decisions, they should be given the opportunity to engage in SDM.⁽⁷⁾ Strategies to increase SDM for medication decisions may include providing residents and health-care providers with SDM resources such as decision aids, educational materials, or use of "what matters most".^(5,8) In partnership with stakeholders, our team developed a behaviour-based framework for implementing deprescribing in LTC, which included co-developing several SDM resources to support medication decision-making.⁽⁹⁻¹¹⁾ The aim of this study was to understand the experience of LTC

homes as they implemented these SDM resources to support medication decisions.

METHODS

We used a quality-improvement approach⁽¹²⁾ to pilot SDM resources, and qualitative thematic rapid analysis^(13,14) to analyze data.

Participants

We recruited four Ontario LTC homes; two participated throughout. Two staff representatives from each site (suggested by respective Directors of Care) joined the six research team members and eight LTC stakeholders who had been involved in SDM resource design to comprise an Advisory Group.

Implementation of SDM Resources

The SDM resources (Table 1), which served as basis of the implementation strategy, were co-designed with LTC stakeholders to promote a common description of SDM and to empower caregivers and residents to take part in SDM.⁽⁹⁾ Figure 1 presents the study approach. Participating LTC sites conducted two Plan-Do-Study-Act (PDSA) cycles.^(15,16) At an initial virtual Advisory Group meeting, we introduced site representatives to the study objectives and timeline, outlined the SDM steps, described the co-designed SDM resources, and discussed ideas for implementation strategies. We then asked sites to conduct a PDSA cycle by selecting SDM resources and an approach for implementation, monitoring use of these resources, and reporting back on outcomes of implementing the SDM resources at another Advisory Group meeting two months later. At these meetings, the site representatives shared their experiences implementing the SDM resources and discussed feedback from other members to help them decide how to approach a second cycle. This process was repeated. After each Advisory Group meeting, one researcher contacted site representatives to ascertain needs for further support.

Data Collection and Analysis

We used rapid qualitative analysis (Figure 1).^(13,14) Data sources included Advisory Group meeting transcripts (audio recorded and transcribed verbatim) and meeting field notes completed by the research team/staff. Five research team members (LM, LH, BF, WT, EG) read meeting transcripts and field notes, then wrote analytical memos (Appendix A). They then reviewed all analytical memos and met virtually to gain consensus on themes. Analytical memos and transcripts from the analysis meetings were used by three team members (LM, BF, WT) to summarize site experiences and overall themes, which were subsequently confirmed by the Advisory Group.

Approvals

This study was approved by the Bruyère Continuing Care Research Ethics Board (Protocol # M16-21-024). Site representatives signed Site Agreements Forms and all members of the Advisory Group completed verbal consent forms prior to recording of meetings.

RESULTS

We identified four LTC sites willing to participate. Two sites withdrew due to competing demands from the COVID-19 pandemic. The remaining sites were both urban (one non-profit, one private/for-profit) with approximately 170 residents each. Site representatives were Directors of Care or nurses in leadership roles.

Story of Site 1

This site engaged with their pharmacist and physicians following the first Advisory Group meeting. Despite our study aim of evaluating implementation of SDM resources, the group at this site chose proton pump inhibitor (PPI) deprescribing as an implementation focus.

The pharmacist provided a list of residents taking PPIs and the deprescribing.org deprescribing guidelines app⁽¹⁷⁾ to physicians to determine resident eligibility. The physician

TABLE 1.
Resources^a provided to support shared decision-making

<i>Resources</i>	<i>Description</i>
Shared decision-making guide	Outlines process for making choices about medications. Designed for people living in LTC homes, their families, caregivers, and health-care providers so that everyone works together to make decisions.
Infographic	Summarizes key steps from the guide. Encourages residents and their families to take part in conversations. Serves as a reminder for health-care providers and staff
Cue card	Outlines key concepts, can be shared with residents and their families. Contains prompting questions to help residents and their families start a conversation with their health-care provider.
Medication record	Helps residents and their families share details about their medication history and experience. Can be provided to residents and their families as people are moving into LTC.
Videos	Series of videos modelling example shared decision-making conversations. Can be shown to residents and their circle of care to show them what shared decision-making conversations look like

^aAll resources are available for download from our website (<https://deprescribing.org/deprescribing-in-ltc-framework/>).

communicated reasons for deprescribing, pros/cons, how to monitor, and when the drug may be restarted with eligible residents’ families, and provided a PPI deprescribing pamphlet.^(17,18) Information about PPI deprescribing was provided to staff and included in a Family Council newsletter. Site representatives later said they aimed to use PPI deprescribing to promote discussion between clinicians and residents/caregivers and to lay a foundation for SDM. However, the SDM resources were not explicitly incorporated into this process and the physicians later said they were unaware of these resources. The site representative said they had separately provided the SDM infographic to nurses to help them communicate with families. SDM cue cards were left at the reception desk, but few were picked up. The site reported limited engagement with the SDM resources. One family member commented positively on being more involved in medication discussions. This site attempted to assess the rate of PPI deprescribing as their outcome measure but found the short time between Advisory Group meetings to be a barrier. Future plans included introducing the SDM cue card at admission and using it at care conferences, as well as expanding deprescribing to other medications. They also found the SDM video “powerful”, although it was not clear to the Advisory Group how it was used. This site was eager to improve medication decision-making, but acknowledged that by focusing on PPI deprescribing they may have “lost sight” of the SDM focus of the intervention.

Story of Site 2

This site began by engaging with residents/families, and registered nurses and registered practical nurses. They used the SDM cue cards and infographics with a small number of care conferences where residents/families were present, along with medication lists to stimulate discussion, relating that these were well received. Some residents were already involved in medication decisions and were receptive to

receiving the resources; however, other residents/caregivers did not have the cognitive capacity or were not interested in being involved in medication decisions. Representatives indicated that the SDM video was helpful though it was not clear to the Advisory Group how it was used. This home did not explicitly define a SDM outcome, but reported on subjective use of resources and perceived resident/caregiver interest. This site was also highly engaged and motivated to have more involvement from residents and caregivers in medication decisions. They described future plans to distribute the cue card and infographic at admission; to educate personal support workers (PSWs) and social workers regarding how to use these resources; and to have providers watch the SDM video so that they could help support and “train” residents to participate in SDM discussions.

DISCUSSION

Participating LTC sites were enthusiastic about the prospect of greater resident and caregiver involvement in medication decisions, and responded positively to SDM resources. However, we found that SDM resources to support medication decision-making were not widely implemented in either site.

A 2017 review⁽¹⁹⁾ of barriers and facilitators to implementing SDM in LTC suggested that implementation requires a culture that supports SDM, appropriate education and training, and supportive resources. While we provided the SDM resources to site representatives (that our team had co-developed with other LTC stakeholders) and oriented them to the resources, we did not provide additional staff or clinician education to avoid overwhelming already busy people. As one site decided on a particular drug class (PPIs) as a focus for introducing SDM in their home (rather than implementing the SDM resources) and the other identified a need for SDM education for all staff, we considered that our initial explanation of the SDM process had not been adequate. It was

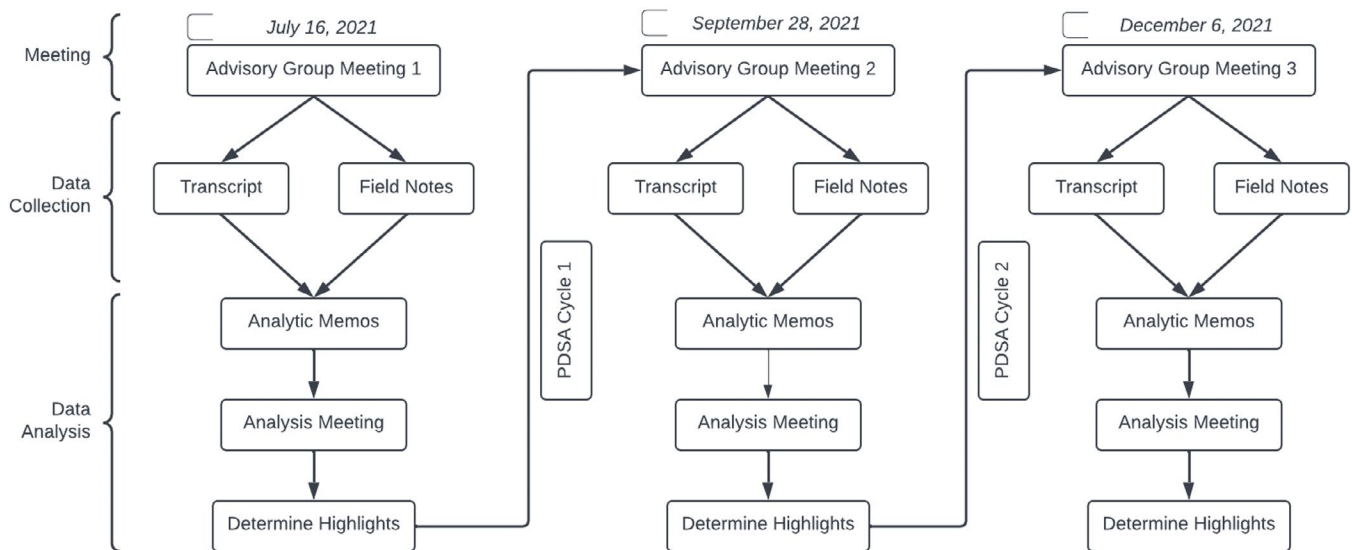


FIGURE 1. Timeline of project implementation

unclear whether we reached a shared understanding with staff, health-care providers, and residents/caregivers at the sites around the many facets of SDM, or how it differs from the mandatory informed consent process for medication changes in LTC. This confusion has been highlighted previously.⁽²⁰⁾ Qualitative data,^(21,22) including Canadian LTC data,⁽⁵⁾ suggest that residents/caregivers need to be encouraged to participate in decisions, and provided with clear opportunities and explicit pathways to do so while respecting their personal desired level of involvement in decision-making. Experts have described how SDM tools and resources alone are insufficient to drive meaningful change, but that tools need to be considered along with structures, environment, and skills.^(23,24) Previous qualitative studies on SDM in LTC⁽⁷⁾ have found that residents/caregivers have different desired levels of involvement in medication decisions and this may also influence the uptake of SDM resources.

We co-designed our SDM resources with people living and working in LTC. However, when we introduced the resources into LTC homes, we found that people had challenges implementing them despite the co-design process. For implementation of SDM in LTC, our findings demonstrate the importance of carefully considering factors such as organizational culture and ownership among all involved, clear pathways for integrating SDM, and education and training. Sites identified opportunities such as education and training, as well as using defined points such as admission medication reviews and care conferences, to incorporate SDM. Sites also identified that LTC staff such as PSWs and social workers should play a larger role in SDM given their close relationship with residents and caregivers. A 2022 review on SDM in LTC⁽²⁵⁾ has also highlighted the importance of staff communication skills training and fostering a culture to support SDM. Finally, implementation efforts should further include clear objectives, documentation, and data collection with dedicated facilitation and support.⁽²⁶⁾

Our study included only two LTC homes and our choice to minimize participant burden during the COVID-19 pandemic (i.e., minimal clinician/staff education/interaction with the research team, allowing sites to select their own PDSA plan and outcomes measures, data collection limited to Advisory Group meetings) likely affected implementation, and the depth and richness of the data. Additionally, our research team's reputation as a producer of deprescribing guidelines may have influenced Site 1's decision to move ahead with a PPI deprescribing strategy as a narrowly focused intervention with readily available tools outlining risks and benefits with steps for deprescribing. In this way, we wonder if they felt health-care providers could consider and deliver complex information more easily and efficiently. Complexity of information and limited time for conversations has been identified by others as barriers to SDM conversations in LTC.⁽⁷⁾ Education materials that outline risks and benefits (e.g., decision aids) have been identified as tools that would facilitate shared decision-making about specific drug classes.⁽⁸⁾ Finally, while we provided an opportunity for coaching to sites during the

PDSA cycles, this was rarely accessed by site representatives and so there was little chance to identify opportunities for additional support between Advisory Group meetings.

Our study adds to existing evidence showing that simple provision of SDM resources in LTC may not be sufficient to drive SDM approaches, even with sites who are engaged. Ongoing work in the field of SDM in LTC includes a Danish complex intervention using health-care provider education, a reflection tool for staff to evaluate symptoms, and a dialog tool to facilitate conversations with residents/caregivers about use of psychotropic medications in residents with dementia.⁽²⁷⁾ Future implementation efforts for SDM likely requires this type of active complex intervention, including supports such as education/training for health-care providers, staff and residents/caregivers, coaching/facilitation, decision-support tools and other structures to facilitate SDM.

ACKNOWLEDGEMENTS

We would like to acknowledge the long-term care homes that participated in this project, along with the advisory group members who provided feedback throughout the project.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal's* policy on disclosing conflicts of interest and declare that we have none.

FUNDING

This publication is supported in part with funding from the Government of Ontario through the Ontario Centres for Learning, Research and Innovation in Long-Term Care hosted at Bruyère. The views expressed herein do not necessarily reflect the views of the province.

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APPENDIX A. TEMPLATE FOR ANALYTIC MEMOS

Instructions: Investigators and staff will create analytical memos as they read through the Advisory Group transcripts and field notes. Analysts will notice interesting patterns in the data, or will experience insights into the meaning of the data, and will record this information in a memo. These analytical memos will inform subsequent Advisory Group meetings.

Analyst Name: Date:
Advisory Group meeting date:
Elements and aspects of the data that stand out.
General patterns and insights.
Learnings about the characteristics of the people participating and the factors that contributed to their participation (Reach – consider both people participating in the Advisory Group meetings, and at the sites):
Learnings about how people feel about participating in the testing of these resources
Learnings about mechanisms that are established to facilitate regular engagement in shared decision-making in medication management, as well as unintended consequences of these efforts (Effectiveness, Efficacy):
Learnings about the resources people are trialling (or interested in trialling), whether they were adapted, how they were used, challenges and opportunities, recommendations for changes and to what extent they were delivered (Implementation):
Learnings about success (or not) in implementing resources aimed at improving peoples’ ability to participate in shared decision-making about medications:
Learnings about plans for sustaining actions that support change, including what might be needed to ensure successful implementation in other sites (e.g. infrastructure, policy, champions/leads emerging, operational procedures, what government needs to do etc) (Maintenance)
Other comments: