Feasibility of Rapidly Developing and Widely Disseminating Patient Decision Aids to Respond to Urgent Decisional Needs due to the COVID-19 Pandemic

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To meet urgent decisional needs of retirement/nursing home residents and their families, our interdisciplinary stakeholder team rapidly developed and disseminated patient decision aids (PtDAs) regarding leaving one’s residence during the COVID-19 pandemic. The development steps were as follows: identify urgent decisional needs, develop PtDAs using the Ottawa Decision Support Framework template and minimal International PtDA Standards, obtain stakeholder feedback, broadly disseminate, and incorporate user feedback. Within 2 wk, we developed 2 PtDAs for retirement and nursing home living environments that were informed by decisional needs (identified from public responses to related media reports), current pandemic regulations/guidance, and recent systematic reviews. Within 3 wk of their dissemination (websites, international PtDA inventory, Twitter, Facebook, media interviews), the PtDAs were downloaded 10,000 times, and user feedback was positive. Our expert team showed feasible rapid development and wide dissemination of PtDAs to respond to urgent decisional needs. Development efficiencies included access to a well-tested theory-based PtDA template, recent evidence syntheses, and values-based public responses to media reports. Future research includes methods for rapidly collecting user feedback, facilitating implementation, and measuring use and outcomes.

Keywords
decisional needs, development methods, dissemination, Ottawa Decision Support Framework, patient decision aid, shared decision making

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Introduction

“If you can get your relatives out of seniors’ homes, try to do so as fast as you can,”1 was the headline of a Canadian newspaper on April 2, 2020. At this early phase of the pandemic, the paper reported >600 COVID-19 outbreaks in retirement and nursing homes.1 This evoked significant media coverage and strong emotional public responses, with hundreds of posted comments. By May 25, Canada had the highest proportion of deaths (>80%) occurring in long-term care among 37 Organisation for Economic Co-operation and Development countries.2

Because many families were grappling with the decision to temporarily move a resident from a retirement or nursing home during the pandemic, 3 authors (D.S., N.E., A.M.O.) collaborated in early April to determine if a patient decision aid (PtDA) could help families facing this quandary. PtDAs3 make explicit the decision being considered; provide information on options, benefits, and harms; and help patients/families clarify their values

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for outcomes/features of options. The Ottawa Decision Support Framework is the most commonly used framework guiding PtDA development. Its main premise is that decision quality improves when patients’/families’ decision-making needs are addressed. Common manifestations of the difficulty in making decisions are feeling uninformed, lacking access to information, feeling unclear about personal values, and feeling unsupported in decision making. A systematic review of 24 randomized trials evaluating PtDAs, developed according to the Ottawa Framework, revealed that they were superior to usual care in addressing decisional needs and improving decision quality.

PtDAs developed according to the Ottawa Framework also meet the International PtDA Standards (IPDAS). However, PtDA development and evaluation often takes more than 1 y, which is too long to address urgent emerging decisional needs. Our objective was to rapidly develop and disseminate a PtDA to meet retirement or nursing home residents’ and families’ decision-making needs regarding location of residence during the COVID-19 pandemic.

Methods

We designed and used an expedited Ottawa PtDA development process (Table 1). First, we rapidly assessed the urgent need for a PtDA.

Next, we established an interdisciplinary stakeholder team (nurses, social worker, physicians, physiotherapist) with expertise in PtDA development/evaluation (D.S., A.M.O.), care of the elderly (N.E., S.S.), local health governance of seniors’ care (C.L., K.B.), counseling patients/families on care options on discharge from hospital (J.L.), and advising provincial governments on medical management of COVID-19 (P.A., S.S.). Team members had either faced the decision about moving a family member into a retirement or nursing home within the past 5 y (n = 3) or were currently facing the decision during the pandemic (n = 1).

Then, we drafted 2 PtDAs using the well-tested Ottawa Framework template. Each PtDA was circulated for iterative feedback from our stakeholder team. Next, the PtDAs were translated into French and disseminated broadly. Users were invited to provide feedback on the website, and we planned to modify the PtDAs, if necessary, based on the feedback.

Results

Our initial rapid assessment indicated there was no available PtDA on location of residence during the pandemic. The PtDAs were justified by the families’ and residents’ decision dilemma stemming from the risks of COVID-19 in retirement and nursing homes, the publics’ response to controversial media, and changes in nursing home regulations specific to COVID-19.

A key source for identifying residents’/families’ decision-making needs were the public’s 298 comments regarding the April newspaper articles. Many held opposing views on the best course of action. Several commented on the decision dilemma indicating reasons to leave a retirement/nursing home during the pandemic or to stay. It was apparent some readers were not familiar with changes in provincial regulations facilitating discharges and readmissions to nursing homes during the pandemic. On April 3, one public health official’s special statement focused on the decision difficulty:

I totally understand concerns that families have about their loved ones who reside in retirement or long-term care homes. Some families are considering whether to take loved ones out of their retirement or long-term care home. This is a challenging decision . . . a family would need to think about.

Since our main target audience consisted of Ontario residents, their substitute decision makers, and other family members, we used sources relevant to that province (legislation, policies). The PtDAs included a self-assessment
| PtDA development process<sup>10–12</sup> | **Prepandemic Process** | **Pandemic Process** |
|-----------------------------------------|--------------------------|-----------------------|
| **IPDAS**<sup>8,10</sup> | **Ottawa**<sup>11,12</sup> Based on ODSF and IPDAS | **Expedited Ottawa** Based on ODSF and IPDAS |
| Consider rationale for developing PtDA: initial stimulus, available PtDAs, decision dilemma, numbers affected, practice and preference variation |
| Explore: initial stimulus, available PtDAs (A to Z PtDA Inventory)<sup>13</sup> | Consult experts and review: practice guidelines, systematic reviews, decision analyses; statistics; practice atlases, patient preference studies |
| Rapidly assess urgent need for PtDA: initial stimulus, available PtDAs (A to Z PtDA inventory<sup>13</sup>); consult available experts and scan readily available information |
| Define scope, purpose, target audience |
| Yes | Yes |
| Assemble steering group: clinicians, a patients, b other experts/stakeholders |
| Yes | Yes |
| Clinicians, senior care administrators, PtDA researchers/developers (no residents included) |
| Design |
| √ Assess patients’ and clinician’s views on decisional needs |
| √ Tested assessment methods |
| √ Procedures involved |
| √ Field testing (alpha testing) |
| √ Field testing (beta testing) |
| Determined format and distribution plan |
| Used tested Ottawa template |
| Available reviews, regulations, policies |
| Determine format and distribution plan |
| Used tested Ottawa template |
| Review/synthesize evidence |
| Available reviews, regulations, policies |
| Review/synthesize evidence |
| Available reviews, regulations, policies |
| Meet IPDAS qualifying criteria<sup>8</sup> (describes condition, index decision, target audience, provides options, positive and negative features, clarifies values for positive/negative features) |
| √ Meet IPDAS criteria to minimize risk of bias (compares positive/negative features with equal detail; probabilities, if used, compare same denominators; includes developers’ credentials, funding sources, conflicts of interest, date of last update, readability levels, references to scientific evidence) |
| √ Procedures involved |
| Consider relevant IPDAS quality criteria<sup>8,14</sup> (natural course of the condition if no action taken; procedures before, during, and/or after the health care option; describes options’ outcome probabilities using event rates; compares probabilities of options over the same period of time; uses same scales in diagrams comparing options) |
| √ Field testing (beta testing) |
| Limited to 1 steering group member who was currently making the decision with a family member |
| Field testing (beta testing) |
| Limited to some steering group members who are potential users as clinicians or as family members who decided for their own families |
| Procedures involved |
| Procedures involved |

<sup>a</sup> Clinicians, senior care administrators, PtDA researchers/developers (no residents included)

<sup>b</sup> Patients included in steering group included family members who decided for their own families

(continued)
to determine if personal care needs could be met at the family’s home, a home safety assessment, and suggestions to discuss care needs with current care providers.\textsuperscript{20–22} Statements for the values-clarification exercise were informed by public responses to media reports. The final PtDAs met all IPDAS criteria (qualifying criteria, criteria to minimize risk of bias). The Flesch-Kincaid readability levels were grades 6.7 and 7.1. The PtDAs were endorsed by the Canadian National Institute of Ageing.\textsuperscript{23}

The English and French versions of the PtDAs were disseminated on the Ottawa Hospital Research Institute PtDAs website,\textsuperscript{16} the National Institute of Ageing website,\textsuperscript{23} and the International A to Z PtDA inventory.\textsuperscript{13} They were also promoted through our contacts, including front-line clinicians who work directly with residents/families, organizations having outreach to seniors (Family Councils Ontario, Canadian Association of Retired Persons), and on social media (Twitter, Facebook, Shared@Shared Decision Making Network Facebook). The PtDAs were discussed in 4 media interviews and 16 media articles (e.g., Canada\textsuperscript{24} the United States\textsuperscript{25,26}) from April 11 to May 3, 2020. The PtDAs were downloaded 10,000 times within the first 3 wk and 17,953 times as of July 31, 2020 (Figure 1).

Feedback was received from 3 users. One user thanked us for “the tools that were of great interest” and reported a typo on the French version. The second said, “Thank you to you and your team for putting out resources that will allow families to make informed decisions about their loved ones during this pandemic. My wife, 51 lives with dementia at a long-term care home. I found your document to be most helpful.” A social worker at a Canadian publicly funded rehabilitation facility sent feedback requesting training in using these PtDAs with their residents.

Discussion

Our expert team demonstrated feasible rapid development and wide dissemination of PtDAs to respond to urgent decisional needs due to COVID-19. Efficiencies in the development process were having access to a well-tested theory-based PtDA template, recent evidence syntheses, values-based public responses to media reports, and extensive experience in developing PtDAs. Our findings led to the following considerations.

 Expedited design of PtDAs is feasible. IPDAS design processes include patient/clinician decisional needs assessments, format and distribution identification, and review/synthesis of the evidence (Table 1).\textsuperscript{10} Often, the needs assessments are quite formal, although a more
recent approach is to include PtDA users as part of the
development team.4,29 Our stakeholder team had mem-
ers who were positioned to use the PtDAs as clinicians
and sometimes as decision makers for their own families.
Fortuitously, the intensity of the public’s response to the
newspaper articles facilitated assessment of families’
decisional needs. However, our stakeholder team should
have included residents who were facing this decision
and a broader range of family members.

Regarding the format and evidence, our expert team
used the well-tested Ottawa Framework PtDA tem-
plate.11 The evidence on home versus residential/nursing
home was limited by its generalizability to pandemic
conditions. Moreover, the evidence on COVID-19 was
often unavailable or continuously changing. We incorpo-
rated links to sources (e.g., nursing home regulations,
public health recommendations) so that users had access
to up-to-date information.

Expedited field-testing methods when using a well-
tested PtDA template need refinement. IPDAS describes
alpha testing with patients and clinicians who have made
the decision to assess comprehensibility, acceptability,
and usability and beta testing with patients and clinicians
facing the decision to assess feasibility.10 Our stakeholder
team included clinicians who provided feedback. Although
we invited feedback from users on the usefulness of the
PtDAs, we had few respondents. Low responses may
have been due to the request for feedback on only one
page where downloads were possible. Moreover, it may
be unrealistic to expect high response rates from users
during a crisis. Future studies should determine how to
obtain user feedback more formally after rapid disser-
mination. For example, program the website to provide
a pop-up questionnaire eliciting feedback from those
who download the PtDAs; however, the ethics review
for such a strategy may delay dissemination.

Expedited dissemination and measuring use/outcomes
need refinement. We used several strategies, previously
described by PtDA developers, to broadly disseminate
them.30,31 The PtDAs were delivered online, endorsed by
the National Institute of Ageing,23 promoted through
organizations for seniors, and discussed in media inter-
views and social media. Dissemination was likely facil-
itated by the urgent need in the pandemic crisis. The
number of media interviews and downloads were highest
around the peak of COVID-19 cases (Figure 1).

In summary, it was possible to rapidly develop and
disseminate PtDAs when there was an experienced team
with access to a well-tested PtDA template and synthe-
sized evidence. A rapid development approach is appro-
priate for time-sensitive PtDAs, but there needs to be
adequate support, including experienced developers, to
avoid poor-quality or biased PtDAs. Future research is
required to determine how best to engage more target
users in the development and dissemination process, to
identify efficient ways to gather more rigorous feedback
during development and dissemination, and to measure
actual PtDA use and resident/family outcomes.

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**Figure 1** Daily patient decision aid (PtDA) downloads (solid line) and 10 media interviews/reports mentioning the PtDAs (black dots) contrasted with the daily number of new cases of COVID-19 in Canada27,28 (dotted line).
References
1. Picard A. If you can get your relatives out of seniors’ homes, try to do so as fast as you can. The Globe and Mail. April 2, 2020. Available from: https://www.theglobeandmail.com/canada/article-if-you-can-get-your-relatives-out-of-seniors-homes-try-to-do-so-as/
2. Canadian Institute for Health Information. Pandemic experience in the long-term care sector: how does Canada compare with other countries? 2020. Available from: https://www.cihi.ca/sites/default/files/document/covid-19-rapid-response-long-term-care-snapshot-en.pdf
3. Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2017;(4):CD001431.
4. Vaisson G, Provencher T, Dugas M, et al. User involvement in the development of patient decision aids: a systematic review. Med Decis Making. 2019. Available from: https://osf.io/qyfkp/
5. Stacey D, Legare F, Boland L, et al. 20th anniversary Ottawa Decision Support Framework part 3: overview of systematic reviews and updated framework. Med Decis Making. 2020;40(3):379–98.
6. Hoevel L, O’Connor AM, Lewis KB, et al. 20th anniversary update of the Ottawa Decision Support Framework part 1: a systematic review of the decisional needs of people making health or social decisions. Med Decis Making. 2020;40(5):555–81.
7. Hoefel L, Lewis KB, O’Connor AM, Stacey D. 20th anniversary update of the Ottawa Decision Support Framework part 2: sub-analysis of a systematic review of patient decision aids. Med Decis Making. 2020;40(4):522–39.
8. Joseph-Williams N, Newcombe R, Politi M, et al. Toward minimum standards for certifying patient decision aids: a modified Delphi consensus process. Med Decis Making. 2013;34(6):699–710.
9. Ottawa Patient Decision Aids Research Group OHRI. Ottawa Decision Support Framework training in communication skills when providing decision support. 2019. Available from: https://decisionaid.ohri.ca/docs/decision Coaching_communication.pdf
10. Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ, Van der Weijden T. A systematic development process for patient decision aids. BMC Med Inform Decis Making. 2013;13(S2):1–5.
11. O’Connor A, Stacey D, Saarimaki A, et al. Ottawa Patient Decision Aid Development eTraining. 2015. Available from: https://decisionaid.ohri.ca/eTraining/
12. Patient Decision Aids Research Group OHRI. Development methods for Ottawa patient decision aids. 2019. Available from: https://decisionaid.ohri.ca/methods.html
13. Patient Decision Aids Research Group OHRI. A to Z inventory of decision aids. 2020. Available from: https://decisionaid.ohri.ca/AZinventory.php
14. Elwyn G, O’Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. Br Med J. 2006; 333(7565):417–22.
15. Legare F, Kearing S, Clay K, et al. Are you SURE? Assessing patient decisional conflict with a 4-item screening test. Can Fam Physician. 2010;56(8):e308–14.
16. Ottawa Hospital Research Institute. Patient Decision Aids Research Group. 2020. Available from: https://decisionaid.ohri.ca
17. Ontario Government. O. Reg. 83.20: GENERAL filed March 24, 2020 under Long-term Care Homes Act, 2007. S.O. 2007, c.8. 2020. Available from: https://www.ontario.ca/laws/regulation/r20083
18. Grant K, Stueck W. Families face tough call over removing loved ones from long-term care. Globe and Mail. April 3, 2020. Available from: https://www.theglobeandmail.com/canada/article-families-face-tough-call-over-removing-loved-ones-from-long-term-care/#comments
19. Public Health Ottawa. Special statement from Dr. Brent Moloughney, Associate Medical Officer of Health. 2020; Available at: https://www.ottawapublichealth.ca/en/public-health-topics/novel-coronavirus.aspx?utm_source=OPH&utm_medium=Home_Page_Banner&utm_campaign=Coronavirus&utm_content=Home_Page_Banner_OPH
20. Boland L, Légaré F, Perez MMB, et al. Impact of home care versus alternative locations of care on elder health outcomes: an overview of systematic reviews. BMC Geriatr. 2017;17(1):20.
21. Blanchet R, Edwards N. A need to improve the assessment of environmental hazards for falls on stairs and in bathrooms: results of a scoping review. BMC Geriatr. 2018;18(1):272.
22. Edwards N, Dulai J, Rahman A. A scoping review of epidemiological, ergonomic, and longitudinal cohort studies examining the links between stair and bathroom falls and the built environment. Int J Environ Res Public Health. 2019;16(9):1598.
23. National Institute on Ageing. Think tank focused on the realities of Canada’s ageing population. 2020. Available from: https://www.nia-ryerson.ca/
24. Richard J. Seniors still hardest hit by COVID-19 pandemic. 2020. Available from: https://torontosun.com/life/relationships/0503-lifemenational
25. Donato A. Canadians share why they did or didn’t remove a parent from care: here’s how two Ontarians answered, “Should I bring my parent home?” Huffington Post. 2020. Available from: https://www.huffingtonpost.ca/entry/decision-longterm-carehomes-canadians_ca_5e9f82d3c3b662e5b839b085?guccounter=1&guce_referrer=aH R0cHM6Ly93d3cuZ29vZ2xlLmNvbS8&guce_referrer_sig =AQAAAL8ekM3DuyBt-culB7_BA62DuUn2E3rnT8 TnmViDLYldkWEZhC793GDY5dxaAXSrbrPRiZkY7HX XL-BvvEoO3d0S3JokiW5YtGe83yjB43-15rpm8nyhjB uGuLuzY4QtO3YhVXHWU6t-i6jbegeJyViY13RSqXjQvm km5wkkAp
26. Graham J. Banned from nursing homes, families need to know if their loved ones are safe. *CNN Health*. May 1, 2020. Available from: https://www.cnn.com/2020/05/01/health/family-nursing-home-elderly-care-coronavirus-wellness-partner/index.html

27. University of Toronto Libraries. COVID-19 data and statistical sources. 2020. Available from: https://mdl.library.utoronto.ca/covid-19/data

28. Soucy JPR, Berry I. Covid19Canada/timeseries_canada/cases_timeseries_canada.csv. 2020. Available from: https://github.com/ishaberry/Covid19Canada

29. Witteman HO, Dansokho SC, Colquhoun H, et al. User-centered design and the development of patient decision aids: protocol for a systematic review. *Syst Rev*. 2015;4(1):11.

30. Elwyn G, Scholl I, Tietbohl C, Mann M, Edwards AG, Clay C. “Many miles to go …”: a systematic review of the implementation of patient decision support interventions into routine clinical practice. *BMC Med Inform Decis Mak*. 2013;13(suppl 2):S14.

31. Stacey D, Suwalska V, Boland L, Lewis KB, Presseau J, Thomson R. Are patient decision aids used in clinical practice after rigorous evaluation? A survey of trial authors. *Med Decis Making*. 2019;39(7):805–15.