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Authors

Katherine McKenzie,[1]
Lynn Martin,[2]
Hélène Ouellette-Kuntz[1,3]

[1] Department of Public Health Sciences, Queen's University, Kingston ON

[2] Department of Health Sciences, Lakehead University, Thunder Bay ON

[3] Ongwanada, Kingston ON

Correspondence

lynn.martin@lakeheadu.ca

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Understanding Implementation of Frailty Measures Among Adults with Intellectual and Developmental Disabilities

Abstract

As the general population ages, there has been greater interest in frailty measures to inform clinical practice and policy decisions. The population of adults with intellectual and developmental disabilities is also aging, and Canadian policymakers have expressed the need to monitor and treat their aging-related conditions as early as possible. Outside of Canada, two research teams in the field of intellectual and developmental disabilities have developed frailty measures, although neither frailty measure has yet been used to support policymaking. The purpose of this study is to understand the factors contributing to implementation of a frailty measure in populations of adults with intellectual and developmental disabilities. Key informants from each research team were interviewed about knowledge translation experiences. Interview questions were guided by the World Health Organization's Ageing and Health Knowledge Translation Framework, which is used to integrate evidence-based strategies and aging-related health policy, processes, and programmes. Transcripts were subsequently analyzed using the framework approach. Key findings included the following: To be implemented in practice, a frailty measure must be brief, relevant, and inform care decisions. The interviews revealed actions that should be taken prior to knowledge translation. These actions include ensuring that the frailty measures are valid and have a clear purpose, and collaborating with appropriate knowledge users. Linkages between frailty researchers and practitioners and policymakers are key to successful implementation of measures developed. Lessons from this study may be used to implement frailty measures in a Canadian population of older adults with intellectual and developmental disabilities.

As the number of Canadian older adults (65 years and older) reached nearly 5 million in 2011 (Statistics Canada, 2012), health care providers face an increase in both the number and types of health, economical, and social challenges (Lefebvre & Goomar, 2005). It is well-known that older adults are at risk of chronic conditions, mobility issues, dementia, and mental health problems (Taylor, 2014). Such concerns have led researchers to develop and use measures of frailty to better identify at-risk older individuals. Frailty is understood to be a multidimensional construct with physical, mental, physiological, social and environmental factors (Rodríguez-Manas et al., 2013). It is associated with increasing age and adverse outcomes (e.g., falls, decreased mobility, institutionalization, hospitalization, and death) (De Lepeleire, Iliffe, Mann, & Degryse, 2009; Rockwood, 2005).

On average, the population of adults with intellectual and developmental disabilities (IDD) experiences age-related co-morbidities and vulnerabilities prematurely. For this reason, individuals in this population are often viewed as "old" by age 50 years (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012; Ouellette-Kuntz, Martin, & McKenzie, 2015; Perkins & Moran, 2010; Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013), although this varies depending on IDD severity and diagnosis. Over a decade ago, the Government of Canada's National Advisory Council on Aging made the recommendation to: "regularly monitor [the health of adults with IDD] as early as 40 years of age in order to detect and treat changes in sensory and cognitive functioning and chronic health problems as early as possible" (Government of Canada National Advisory Council on Aging, 2004, p. 7). This acknowledgement is commendable but there is little evidence that the recommendation has led to systematic action. In a population with lifelong disability and frequent co-morbidities, it is a challenge to identify new vulnerabilities and functional declines (Evenhuis, Schoufour, & Echteld, 2013). As a result of increasing longevity (Bittles et al., 2002; Coppus, 2013; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000) and growing numbers of older adults in general (Statistics Canada, 2011), the need to act on the Council's recommendation becomes all the more pressing.

Our recent scoping review revealed that only a few studies have specifically reported on frailty measures among populations with IDD (McKenzie, Martin, & Ouellette-Kuntz, 2016). Brehmer and Weber (2010) were the first to develop a frailty measure while considering the lifelong disability and early aging of this population: the Vienna Frailty Questionnaire for persons with Intellectual Disability (VFQ-ID), followed by the VFQ-ID-Revised (VFQ-ID-R) (Brehmer-Rinderer, Zeilinger, Radaljevic, & Weber, 2013). Three years later, Schoufour, Mitnitski, Rockwood, Evenhuis, and Echteld (2013), as part of the Healthy Ageing and Intellectual Disability (HA-ID) study, published a frailty index for individuals with IDD over 50 years of age. McKenzie, Ouellette-Kuntz, and Martin (2015) also developed a frailty index for home care users with IDD. See the recent scoping review by McKenzie, Martin, & Ouellette-Kuntz (2016), which compares and contrasts these measures.

From these limited results, frailty appears to occur earlier in adults with IDD compared to those without IDD (McKenzie, Ouellette-Kuntz, & Martin, in press; Schoufour et al., 2013). Frailty is associated with the same outcomes afflicting the general population, including institutionalization (McKenzie, Ouellette-Kuntz, & Martin, 2016), disability (Schoufour et al., 2014), sarcopenia (Bastiaanse, Hilgenkamp, Echteld, & Evenhuis, 2012), higher medication use (Schoufour, Echteld, Bastiaanse, & Evenhuis, 2015) and mortality (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2015). While many measures of frailty exist in the general population, these measures may not be suitable to the population of adults with IDD given their life-long disability that can incorrectly appear as indicators of frailty (Evenhuis et al., 2013; McKenzie, Ouellette-Kuntz, & Martin, 2015a).

The existence of frailty measures allows for the possibility of acting on national recommendations to better monitor and detect early changes in functioning through implementation of frailty measures to improve care, inform policy and understanding of aging with IDD. Generally, however, it is difficult to find published literature on frailty assessments in practice, and there is no literature on such implementation for adults with IDD.

Before care providers and policymakers can use frailty tools, researchers must engage in knowledge translation to bridge the "know-do" gap (World Health Organization [WHO], 2006). In Canada, Graham and Tetroe's (2009) definition of KT has been widely adopted in health research: "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" (p. 46). The Canadian health care system increasingly acknowledges KT as an important function in the research process (Lavis, 2006); as such, knowledge users may be receptive to research-based frailty measures. This study aimed to understand the factors contributing to implementation, or lack thereof, of frailty measures in the field of IDD to inform future initiatives within Canada.

Materials and Methods

The study protocol was reviewed and approved by the Queen's University Health Sciences Research Ethics Board.

Recruitment and Participants

We contacted members of the two research teams who have published research on measures of frailty in populations with IDD. Two individuals from each team were interviewed (total N = 4).

Interviews

The development of the interview questions was guided by the World Health Organization's Ageing and Health Knowledge Translation Framework, which provides an approach to integrating evidence-based strategies and aging-related health policy, processes, and programmes (WHO, 2012). This framework has seven key elements:

(1) **Climate and context for research use.** The local context takes into consideration the characteristics, circumstances, and conditions of research and policy practices, with respect to aging and health.

(2) **Linkage and exchange efforts.** The linkage and exchange between researchers and knowledge users, policymakers, and stakeholders can enable informed policymaking and the transfer of research intro practice.

(3) **Creation of new knowledge.** Knowledge creation can influence evidence informed policymaking, if the research is timely, relevant and applicable.

(4) **Push efforts.** Activities by researchers and intermediate groups to push knowledge to the necessary groups in an appropriate format should be jargon-free and highlight actionable messages.

(5) **Facilitating pull efforts.** Efforts to facilitate a pull from knowledge users aim to make it easier for policymakers to acquire relevant research evidence.

(6) **Pull efforts.** Knowledge users embark on pull efforts when they value the use of research and recognize the presence of an information gap.

(7) **Evaluation of efforts to link research to action.** Evaluation is needed on the activities that support the linkage of research to better advise future knowledge translation events.

Interview questions (and probes) were designed to elicit information on participants' experiences implementing a measure of frailty and relationships with knowledge users. Additional information on participants' role in developing frailty measures was noted.

Participants from the same research program were interviewed together for approximately one hour. Interviews were audio-recorded to allow verbatim transcription for analysis.

Analysis

The interview was structured around pre-set research objectives (i.e., understand factors contributing to frailty measure implementation). Pope, Ziebland and Mays (2000) presented a deductive, framework approach to qualitative data analysis, which we applied in this study. The five steps of this approach involve:

(1) **Familiarization.** All authors immersed themselves in the data by reading the two transcripts to become aware of key ideas (referred to as "codes"). Each researcher suggested different ways of understanding and summarizing the findings.

(2) **Identifying a thematic framework.** The authors based coding on the seven core elements of the Ageing and Health Knowledge Translation Framework (WHO, 2012).

(3) **Coding.** The authors independently coded the transcripts according to the framework, and created new codes as needed. Next, the authors reviewed the codes together to reach agreement. Supporting quotes were identified.

(4) **Organizing the index.** The authors structured the codes into major themes.

(5) **Mapping and interpretation.** The researchers reviewed themes and explored the relationships between themes to explain the results.

The analysis adhered to the principles of naturalistic inquiry (Lincoln & Guba, 1985) to ensure dependability, credibility, and transferability.

Results

Selected quotes are included in Table 1 (on the following page) for each of the elements of the Ageing and Health Knowledge Translation Framework (WHO, 2012).

Context

In the Netherlands, only individuals with IDD with high support needs live in care settings, the remainder live in the community with family or in small group homes. Care is organized and provided regionally. No specific organization has a mandate dedicated to aging adults with IDD. Key informants viewed aging issues as the responsibility of all providers regardless of sector (e.g., health, social, disability).

In Austria, care providers vary from province to province, with a blend of non-governmental organizations, government, and private organizations in each of the nine jurisdictions. In Upper Austria, for example, support is determined based on the level of disability, which is identified using one measure. Individuals with IDD often age without extra medical care, as their allotted funds will not cover the cost of additional nursing support. Care plans are also sometimes based on outdated assessments.

Linkage and Exchange Efforts

In the Netherlands, there was no ongoing partnership between frailty researchers and policymakers. While care providers, such as non-profit organizations, may fund extensive research projects, there is no requirement for ongoing exchange of findings. For example, the organization that funded the multi-year HA-ID study required only a final summary report of results. Key informants viewed this partnership positively, and appreciated the freedom to conduct scientific research without intrusion by the funder.

One of the participants also noted the importance of improving the ability to link health data across jurisdictions and at the population-level, as well as permitting researchers to access that data. It was acknowledged that stronger partnerships with government were needed for this to happen. In Austria, more substantial research-stakeholder relationships and linkages appeared to exist. For example, one informant described a working group of service providers and researchers that developed a scale of support needs – though it was noted that this scale was not implemented into practice.

An instance in which the key informant herself played both the role of researcher and service provider, helped to bridge the gap and resulted in a more effective partnership. Here, the researcher worked with employees to develop a tool to understand aging within their clientele that could also objectively determine and prioritize areas for care improvement.

Knowledge Creation

Both groups of key informants spoke to the current use of frailty measures in practice. In the Netherlands, the frailty index has exclusively been used for research purposes. However, the need for a frailty measure that is relevant to practice was recognized by clinicians, who wanted something standardized, brief and easy-to-administer. While the frailty index developed by the HA-ID study team is relevant and timely, it is not likely applicable in its current state. Future work to develop and validate a shortened version is required for it to be used in practice.

In Austria, the frailty measure developed "in-house" by the researcher for the implementation within the organization, and so the focus to date has been on data collection and application to practice by the agency. This data could be useful for future work, for example, determining frailty outcomes and best practices.

Push Efforts

Knowledge was pushed by key informants from the Netherlands using a traditional, academic model, including conferences and published papers. Most of the papers were published in peer-reviewed journals targeting audiences interested in IDD, although some were also published in general aging journals (i.e., *Journal of the American Geriatrics Society*).

Table 1. Selected Quotes to Demonstrate the Ageing and Health Knowledge Translation Framework

KT Framework	*Netherlands*	*Austria*
Context	"We wanted to get an idea about how frail they were, and how they age, and can you compare that with the general population. Are they all frail, and are there any differences between these groups? And not immediately for clinical practice, maybe for information to get to know the population better." "This funding by the government … it's new, they have funding for people, not only aging, but for people with ID, to do research, to stimulate research. So they do care."	"There are different policies within the Lebenshilfe [community living] in Austria. Some are setting up in old people's house, others just want to integrate. They live over there, and they are supported over there, where they are getting older. But then when the medical system is getting higher, then sometimes they will change. Because in the disability services, they operate without nurses, it's a more social, education approach… If you need support for extra medical care, when you are getting older, then this rate they offer you will not cover the cost for more expensive nurse."
Linkage and Exchange Efforts	"…they select the best quality scientific study, but they don't interfere with the content. But you do have to report back…" "I've read studies in other countries where they extract data from general practitioners, but we cannot do that… I think it's technically possible that they're all connected to each other, but I'm not sure how. It's new. It's mostly for care reasons now."	"Employees were asking for a tool to follow up on aging to see which area of the daily living needs more attention- *really* needs- because some say the person is wobbly on the feet, and the other person says no, he can do it well…. My employees are annoyed when they have to fill in a questionnaire that has no point for their daily activities"
Knowledge Creation	"I think [the frailty index] could definitely it could be implemented, but it would have to be shorter. It is really long now and there are some extensive measurements in there. Blood measurements, and the block and block test …it takes a lot of time, and it would not be feasible to implement the full FI into practice. But you could shorten it and validate it again. And then, I think it could be used."	"But we're not a research institute, so we just collect on an individual basis…We do not have the resources to collect data. But it would be possible…You can do it on the individual level and it's very helpful, and on a health planning on the individual level, but we have group homes of six or seven people and they are currently 56 years old or 57, so we know in 10 years the health of the whole group will change, and we will certainly need a nurse for the whole group. So we can follow for all the persons with the [VFQ-ID-R] for health status and decide the time to reassess with the province and when to employ a nurse for the whole group. So you could use it on the higher level as well, in the service provider."

Table 1. Selected Quotes to Demonstrate the Ageing and Health Knowledge Translation Framework (continued)

KT Framework	*Netherlands*	*Austria*
Push Efforts	"I think, as a clinician… it would be very interesting to see if interventions can improve [health], and that's something clinicians are interested in."	"Sometimes there are links between service providers and researchers, but normal, lasting continuations with Lebenshilfe… very often the two systems are not linked in a continuous way. That is atypical what we have here."
Facilitating Pull Efforts	n/a	"There were subjective views… what is the situation for the person, really? …That's why I introduced [the scale]…The other reason is that employees were not sure when to call for a doctor and ask for a thorough health examination. The scale also helps to see OK, in the past 6 months, the person experienced five deteriorations in these areas, so now we should go see a doctor, and tell the doctor about this skill skills lost."
Pull Efforts	n/a	n/a
Evaluation Efforts	"The granters want to hear about [our initial report]. But it's not a real evaluation, because we did not implement anything."	n/a

However, as one of the key informants is a clinician, knowledge is likely pushed out informally as well (e.g., through discussion with individuals with IDD, families, and other staff).

In Austria, the relationship between the research team and the Lebenshilfe of Upper Austria (a community-based agency that provides residential, vocational, and other community-based programs, equivalent to a Community Living agency in Ontario) allowed the uptake of the frailty measure by employees. This research team also pushed knowledge through publication of papers on their measure (i.e., VFQ-ID-R).

Facilitating Pull Efforts

The VFQ-ID-R developers considered the preferences of on-the-ground staff members who provided daily care to individuals with IDD. Care providers did not see the benefit of administering lengthy interviews and questionnaires if they found it redundant without providing any benefit to the individuals for whom they provided care. They desired an objective measure that would reduce the confusion between staff members trying to determine the level of functioning of their clients. Employees were also unsure when to ask for medical attention from a doctor, and requested a formal indicator. As a result, and to meet these practical needs, the items in the VFQ-ID-R are multi-dimensional, encompass areas of functioning of interest to care providers, and emphasize changes in health status and functioning to signal the presence of deterioration and need for action.

Pull Efforts

None of the informants were aware of pull efforts by knowledge users. They remained focused on furthering their research using frailty measures, and less on exploring implementation opportunities.

Evaluation Efforts

None of the key informants had participated in formal evaluation efforts of activities aimed at implementing the measures in practice.

Discussion

The seven elements of the Ageing and Health Knowledge Translation Framework were addressed to varying degrees through the key informant interviews. Both teams were able to speak to the **context,** and explained the role of their respective social and health care systems in addressing aging in the population: neither had an organization specifically dedicated to aging individuals with IDD, and both had systems with a wide range of care setting options. In Austria, there were strong **linkage and exchange efforts**, which was largely due because one of the researchers was also a care provider, and was able to both develop a tool and implement it to improve care in her organization. In the Netherlands, research on frailty was primarily contained to the academic universe, although clinicians and care providers collaborated and were involved in data collection. Both groups were involved in **knowledge creation** – i.e., developing their unique frailty measures. The results were published in academic journals, which reflected their knowledge **push efforts**. However, these journals were primarily in the field of IDD. Publishing in journals that focus on geriatrics or aging in general, rather than on those focused on IDD, may help to increase interest in and knowledge about frailty among those with IDD. The team in Austria was able **to facilitate pull efforts**, by working with the organization to develop a frailty measure that was both scientifically rigorous and helpful to employees who could use it with their clients. Neither group of key informants clearly indicated **pull efforts** and **evaluation efforts.**

The interviews highlight two different approaches to developing a frailty measure, each appearing to have distinct purposes. Having been developed with care providers, the frailty questionnaire (VFQ-ID-R) is used in practice in Austria, whereas the frailty index, developed and validated within an academic environment in the Netherlands, is not. While research is ongoing in the Netherlands, it has ceased in Austria, largely due to limited resources available within the organization for academic endeavours.

These interviews revealed three important actions that should be taken prior to knowledge translation to facilitate uptake of frailty measures in practice and policy in the field of IDD. First, a clear purpose for the frailty measure must be articulated. The need for a clear purpose has previously been identified in frailty-related research as key to determining the approach to measurement (Cesari, Gambassi, van Kan, & Vellas, 2014). In Austria, the measure was developed with the purpose of being an objective indicator of decline in functioning that could inform future care activities (e.g., physician referral, medication monitoring). This specific purpose also aligns with goals of frailty tools in general: to understand frailty and its biology; to diagnose and care planning; to be an outcome measure; and to stratify risk (Rockwood, Theou, & Mitnitski, 2015). The HA-ID frailty index also aligns with these goals, and those related to understanding frailty and risk stratification in particular. To be used as a screening or diagnostic tool, modification of the HA-ID frailty measure is likely warranted.

The second action must be to establish the validity of the frailty measure. Four stages are documented for building a predictive measure in practice: development, validation, impact analysis, and implementation (Adams & Leveson, 2012). In research, the first two stages have plenty of evidence (Rockwood et al., 2015), and our key informants have published multiple articles on development and validation (for example, see Brehmer-Rinderer, Zeilinger, Radaljevic, & Weber, 2013 and Schoufour et al., 2013). However, the next stage should also be explored, and could take the shape of a cost-benefit analysis or an implementation feasibility trial (De Lepeleire et al., 2009).

Our last important action must be to facilitate explicit collaborations with knowledge users familiar with general practice and important outcomes. Both early and continued collaboration are required to ensure that the frailty measures developed are useful, relevant, and appropriate to individuals with IDD and the care providers who will use them. A close relationship can facilitate and support a relatively quick uptake of frailty measures into practice, as evidenced by the use of the VFQ-ID-R in Upper Austria.

These key findings highlight the difficulty experienced by researchers in many jurisdictions in moving research beyond academia. In Ontario (Canada), our research team has developed and maintained good linkages with knowledge users in both practice and policy over the course of the development of a frailty measure specific to adults with IDD since the project's inception. This appears slightly different from the approach taken by the other two teams, who focused on either the research outputs (i.e., the Netherlands) or practice implications (i.e., Austria). Beyond regular discussions with knowledge users to inform the research, the frailty measure developed by our team relies on clinical data obtained from an assessment used as part of regular clinical practice (McKenzie, Ouellette-Kuntz, & Martin, 2015a). Results can also be aggregated for use by policy and decision-makers. It is hoped that this embedded connection to both practice and policy, in addition to continued consideration of the purpose, development stages, and needs of knowledge users (who are also collaborators) will lead to easier implementation of the frailty measure for persons with IDD and facilitate its use in decision-making in Canada.

Key Messages From This Article

People with disabilities. Research shows that people with intellectual and developmental disabilities become frail earlier than people without disabilities. This is important for clinicians and policymakers to know. They must all work together to make sure that research gets used in real life.

Professionals. Brief and relevant frailty measures may be implemented in practice to better serve individuals aging with intellectual and developmental disabilities.

Policymakers. Linkages between researchers, policymakers and practitioners are vital to the development and implementation of measures to support aging care.

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