

Transferable Practices for Knowledge Mobilization: Lessons from a Community-Engaged Health Research Study

Renate Ysseldyk, Angela Paric, and Tracy Luciani

“*Slow and steady wins the race.*”

Aesop (620–564 BC)
In *The Hare and the Tortoise*

Community-engaged health research can have both immediate and lasting impacts, yet is often plagued with various unknowns and unanticipated delays – this can be especially true in hospital settings with older adults. In this informal case study based on the authors’ collective experiences of an unraveling of the research process, the challenges and issues faced in assessing the health benefits of the “Music & Memory” iPod program in a complex continuing care hospital wing are discussed. Specifically, the lessons learned through the processes of acquiring ethical approval to work with a particularly vulnerable population, of effectively measuring the benefits of the program, and of the day-to-day logistical issues are recounted, with suggestions for overcoming these challenges through transferable practices for working with vulnerable or older adults and mobilizing the knowledge gained.

Introduction

Researchers often have grandiose plans. Plans to collect huge amounts of data. Plans to disseminate their findings through the most prestigious and widely read outlets. Plans to change the world. While these ideas are usually well intentioned, they are too often overly ambitious. For example, one avenue through which many researchers see that their work can have immediate but also lasting impacts is by engaging with community partners to facilitate knowledge mobilization and effect change. Community-engaged research provides opportunities to impact community leaders, policy makers, and fellow researchers alike, many from day one. Within a health framework, community-engaged research is “increasingly viewed as the keystone to translational medicine” (Michener et al., 2012). Nevertheless, it is often plagued with various unknowns and unanticipated delays, and this can be especially true in hospital settings with older or vulnerable adults. Here we recount the issues and challenges experienced while assessing the health benefits of a social intervention among complex continuing care patients, offer suggestions for transferable practices for working with vulnerable or

older adults, and describe the lessons we learned along the way – not least that the mobilization of knowledge stemming from community-engaged research is often a slow and steady process.

Background

In the summer of 2014, our team came together for the first time: a brand new faculty member at Carleton University, her new PhD student, and a knowledge broker at Bruyère Continuing Care, which is affiliated with several hospitals and long-term care facilities across the city of Ottawa, Canada. We had plans. Big plans. Our first initiative was to assess the health benefits of an arts-related social intervention (wall mural painting) among older adults living with dementia in a secure long-term care unit (in which residents with age-related conditions, such as dementia, typically live for years). We began to put together the pieces of the project but quickly encountered many barriers. Ethical considerations in working with a very vulnerable population, funding cuts, and logistical issues all quickly collided and our project was grounded before it could even begin.

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While still interested in the health benefits that social interventions – especially those related to the arts – might have among people with complex healthcare needs, we turned our attention to the Music & Memory (Box 1) iPod program that, coincidentally, was about to be rolled out within one of Bruyère’s hospitals, specifically in the complex continuing care wing (in which patients with medically complex conditions receive specialized care, often for several weeks, months, or years). And unlike the long-term care home in which we had made our first research project attempt, this hospital’s Therapeutic Support Services department, which includes volunteer resources, was piloting a new service delivery model; staff and volunteers were trained and keen to try something new, and this project fit. The timing was perfect.

A substantial amount of evidence has shown that music listening is beneficial to health and well-being. This has been demonstrated in various populations, including those living with dementia (e.g., Evans, 2002; Sung et al., 2010). Additionally, we are now discovering that the personalization of such activities, making them more reflective of one’s personal and social identities (Gerdner, 2000; Haslam et al., 2014) can further enhance the benefits of the activity. However, despite some recreational programming offered within hospital settings, patients within complex continuing care units (whose stays are generally much longer than in acute care) are often bedridden and unable to participate in group programming. Thus, there is a need for new activities that can be carried out within patients’ rooms. The Music & Memory program offered one such solution. Yet, while the benefits of the program have been captured qualitatively and anecdotally in many respects (see Sacks, 2007), quantitative evidence in this regard was lacking.

The hospital had already registered with the Music & Memory program and had obtained funding to purchase iPods. Our strategy to determine whether the program would have tangible benefits for patients was to create personalized playlists for each patient and then to quantitatively assess various health and well-being outcomes (e.g., changes in memory and cognition, positive and negative affect, etc.) over a period of two months – before, during, and after the intervention. The program would be piloted in the complex care unit. Due to their medical conditions (e.g., individuals on ventilators, with progressive diseases, and multiple medical issues or limited mobility), patients on this floor typically have longer hospital stays than those on other units. For this reason, they might especially benefit from having their own personalized playlists, while

Box 1. Music & Memory (musicandmemory.org)

The Music & Memory program aims to “help people in nursing homes and other care organizations who suffer from a wide range of cognitive and physical challenges to find renewed meaning and connection in their lives through the gift of personalized music” (Music & Memory, 2016). It begins with a certification process, wherein care professionals are provided with evidence supporting the use of music in healthcare and informed of best practices for obtaining listening devices, building and sharing a music repertoire, as well as engaging with staff and family members. Once certified, care professionals provide iPods with personalized music playlists to patients or residents with the aim of improving memory, socialization, and overall well-being. Music & Memory has gained particular attention for its use among older adults living with dementia. For these individuals, familiar tunes often trigger fond memories and awaken a spirit that otherwise seems consumed by the disease. These effects are captured in the documentary “Alive Inside: A Story of Music and Memory” (www.aliveinside.us).

we could carry out a two-month research study in this wing without the data collection being interrupted by patient discharges. Over time, other hospital employees also joined the project. Their help and expertise were necessary to ensure that the program would run smoothly. Yet, despite piggybacking our health assessments on an existing hospital program that linked closely with our research goals and interests, we still faced many challenges.

Ethics Review Board Challenges

Many of the challenges we encountered occurred before the data collection phase of the project had even begun. The first of these was obtaining ethics approval simultaneously from two different organizations – the university and the hospital’s research institute. In working with a particularly vulnerable population – in this case, patients in a complex care hospital unit – both the researchers’ and (especially) the patients’ interests must be safeguarded. Obtaining ethics approval from both institutions was required, and would minimize the likelihood that either the researchers or patients would be confronted with unanticipated negative outcomes as a result of the study. For example, how often could a researcher or volunteer visit a patient for data collection

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or to deliver the iPod without getting in the way of (or even compromising) their medical care (Davies et al., 1998)? How might our research design need to be tailored to consider patients' health-related limitations? These issues were especially important to consider in the hospital ethics application, which required detailed accounts of what problems might be encountered and how they would be managed. Although such challenges are certainly not new to the world of community-engaged research within hospital settings (Minkler, 2004; Strike et al., 2016), anticipating those challenges before the study can begin is essential. Two simultaneous ethics application reviews (both with institution-specific forms and requirements), multiple revisions (back and forth as both institutions requested different amendments), and nine months later, we finally secured approval from both research ethics boards.

Among the most challenging ethical considerations we faced was the informed consent process. Although most of our patients were not living with dementia, they had other complex health challenges that made either verbal or written informed consent impossible. In some cases, a patient's power of attorney needed to be contacted for consent. After many iterations of our informed consent form with the ethics committees, what we learned was that the consent process needs to be as concise as possible: traditional comprehensive consent forms were simply not appropriate for this population. In our study, we summarized the consent form in brief terms, making sure to include only the most critical information (e.g., a sentence or two for each of the vital sections, such as study purpose, task requirements, and right to withdraw). What we learned from our experience with this unique study population was, much like the plain language recommended for translating policy or research findings to a broad audience, we needed to use brief and simple consent scripts and obtain verbal as opposed to written consent, because it ensured a swifter and more appropriate consent process for patients with mobility restrictions.

Measurement Challenges

Alongside challenges in obtaining ethics approval were various challenges in selecting measurement tools that would be appropriate for our sample. Much like our modified informed consent process, some of the questionnaires we had planned to use – including those we had used in previous research within retirement homes – were not appropriate for this population. How could we create survey questions that were easily interpreted by this group of patients? Some of our participants

could not speak, and so modified versions of our questionnaires needed to be developed such that pointing to the preferred response could be recorded by the researcher. Other participants had limited mobility and could not hold a pen or pencil, resulting in the need for researchers to record responses on their behalf. In an effort to overcome these challenges, we obtained (or created) visual scales for many of our outcome measures, such as Cantril's (1969) Ladder of Life Scale. Gathering data was also more time consuming than anticipated. Patients needed breaks during survey completion. Some questionnaires also triggered memories that patients wanted to discuss. These challenges mainly affected the researchers' timelines for the study, as patients generally did not seem to mind the length of the questionnaire and, in fact, seemed to genuinely enjoy speaking with the researchers (perhaps because some of the patients spent much of their time relatively isolated from the type of social interactions that most of us take for granted on a daily basis, and also because they potentially gained an increased sense of purpose by contributing to a research study in this way (see Gysels et al., 2012)). However, this experience taught us that, in future studies, researchers should carefully consider the appropriateness of the measurement tools for their study participants, set aside more time for survey completion, and be trained and prepared to discuss potentially sensitive information with patients.

Day-to-Day Logistical Challenges

In addition to ethical and measurement challenges faced, there were several day-to-day logistical challenges encountered. Many of these involved the technological aspect of our project. How could we establish and maintain a relationship with the IT department so that we were able to create and update playlists in a timely manner? USB ports on all hospital computers were blocked for security reasons – the IT department needed to know which researchers and volunteers were involved in the Music & Memory program so that USB port access could be swiftly granted. Further to this, several other challenges regarding storing and updating the iPods themselves had to be considered. Where could iPods and other materials be stored so that they were easily accessible to volunteers and yet be safe from theft? What was the best way to keep iPods and their accessories sanitized for infection control? How often could we ask patients whether or not they were satisfied with their playlist without being a bother to either the patient or the IT department? For security reasons, iPods had to be stored in locked cabinets that were only accessible to the researchers and volunteers. Keeping

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the iPods in small plastic bags in the cabinet within a common area on the same floor where a patient resided seemed to work best, while leaving the earphones in each patient's room proved to be most convenient and sanitary.

Despite our best efforts to have someone “with feet on the floor” each day and evening, we underestimated how often patients would want to listen to their iPods. Ideally, all hospital volunteers would be aware of ongoing research projects and know how to help patients participate (by providing access to the iPods, in this case) even when the researchers are not present. In this regard, it is often difficult for a researcher or volunteer to determine when patients would be available (e.g., not during mealtime or a physiotherapy appointment) to listen to their iPods or to spend time with one of the researchers to complete the surveys. Therefore, coordinating with hospital staff is also beneficial, but finding a way to do this without asking too much of an already overloaded workforce presented yet another challenge. Collaboration between researchers, volunteers, and staff not only enables such programs to run smoothly, but also involves those who are most familiar with each individual patient, thereby further safeguarding patient well-being.

The most important lesson that we learned along the way was that having a “community insider” who can share knowledge with everyone involved and obtain their support, from those with daily patient contact to upper level management alike, can make a huge difference. Many layers of staff and managers needed to “buy in” to the project: charge nurses on the floor, the recreation therapist who was the first point of contact with patients, the recreation coordinator who liaised with the information and technology (IT) department, the therapeutic support services director, and the upper management of the research institute. Our “community insider” – the knowledge broker on our team – through many meetings, phone calls, and emails, harnessed the support and guidance needed to make our research project possible.

Knowledge Mobilization Challenges

In the end, although we had planned to collect quantitative data from dozens of participants, only eight complex continuing care patients participated in the Music & Memory iPod program and our associated health study. Such a small sample size limits the scope for statistical analyses; nonetheless, over the course of the two-month project, self-reported life satisfaction increased

while negative emotional symptoms decreased, coinciding with an increased number of music-listening days over time. Moreover, the qualitative responses collected from the participants confirmed that the program had made a positive difference in patients' lives. In a sample of patients living with a variety of complex and chronic health conditions, even the smallest improvements toward quality of life are meaningful – as one of our participants described her music listening: “It gets me away from everything”.

Two years on, our work is having ripple effects within that complex care hospital wing and beyond. We have presented the results of our study at a local conference for practitioners and academics alike (led by the Bruyère Research Institute) devoted to improving the lives of individuals in long-term care (Paric et al., 2015), and at an international academic meeting focused on building better communities and social identities (Ysseldyk, 2016). We have also spoken about the lessons we learned through putting the project together for a university community-engagement event (Ysseldyk & Luciani, 2015), and we have plans for further presentations and publications in this regard.

Our project has been highlighted on the websites of the Bruyère Research Institute and the Music & Memory program – complete with a YouTube video (bruyere.org/en/newsroom?newsid=156) recounting one patient's experience in our study (Bruyère Newsroom, 2016). By using multiple avenues to share or “mobilize” our research, we are increasing the reach of our study to audiences outside academia (SSHRC, 2016), most of whom will neither read the published findings nor attend an academic conference at which we present. For example, the video – which has thus far been viewed nearly 200 times – quickly synthesizes the purpose and impact of our project in plain language and in an accessible format (CIHR, 2015) – an effective and efficient means of spreading the word about the program and our results.

The Music & Memory program has also since been presented to Bruyère's hospital Board of Directors and will soon be carried out within their other hospitals and long-term care homes. Conversations regarding the dos and don'ts of successfully rolling out the program are also taking place among the therapeutic recreation services coordinator and the volunteer resources coordinators at these various institutions. Indeed, the newsroom video and this article itself (reviewed by Bruyère's therapeutic support services management before publication) have provided alternative formats for disseminating the knowledge gained by this project in

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order to impact departmental processes, such as how participants and volunteers will be recruited for involvement in the ongoing Music & Memory program at Bruyère's other sites.

Conclusion

What we gained from the project as researchers was greater insight into what to do – and what not to do – when engaging in community-based research with older or vulnerable adults and then in mobilizing the knowledge outputs. Indeed, we learned numerous key lessons and transferable practices from our experience:

1. Timing in community-based health research is important in order for projects to get off the ground and then run smoothly from inception to completion.
2. Piggybacking a research project on an existing hospital initiative or intervention is helpful for a variety of reasons, including increasing internal support and integrating the research team more smoothly into the institution and its processes.
3. Acquiring ethics approval for working with vulnerable populations from multiple review boards can take several months (or more). Researchers should plan ahead to avoid disappointment, and it is advisable to acquire approval from the (usually) more stringent hospital review board first.
4. A brief, simplified, and verbal informed consent process can make the process more accessible and understandable for study participants from the very start.
5. The use of visual scales and succinct measurement tools for research with older or vulnerable adults is highly recommended.
6. When the project involves a technological aspect, it is important to find a way to keep the technology sanitary and secure, but also accessible to patients and researchers.
7. Involve volunteers as much as possible to avoid overburdening hospital staff while enabling projects to run smoothly.
8. Having a "community insider" on the research team can help gain support from those with daily patient contact to upper-level management alike.
9. Knowledge mobilization in community-engaged research should take advantage of both "community" and "research" resources, thereby increasing the reach to audiences both within and outside of academia—the audiences who will gain the most benefit from knowing about the results.
10. The fruits of researchers' knowledge mobilization efforts in community-engaged research may not be immediately seen, but rather developed over many months or even years following a project's completion.

Further to these lessons learned, this project has had lasting impacts both within the hospital community and within our own research programs. Although we started with grandiose plans for data collection and knowledge mobilization, we learned from our experience that in the practice of community-based health research with vulnerable or older adults, some questions are simply best answered one participant at a time, and the knowledge mobilized as a marathon rather than a sprint. Slow and steady.

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About the Authors

Renate Ysseldyk, PhD, is an Assistant Professor in the Department of Health Sciences at Carleton University in Ottawa, Canada. Her research focuses on social determinants of health among potentially vulnerable populations (e.g., older adults, women who have experienced abuse, individuals who have experienced discrimination). She is interested in the influence of psychosocial factors, and especially particular social group identities (e.g., as a caregiver, a woman, or a person of religious faith), on coping with stressful experiences. Her most recent line of inquiry investigates the identity-affirming effects of music on health and well-being.

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Tracy Luciani, PhD, is a Knowledge Broker within Bruyère Continuing Care in Ottawa, Canada, focusing on improving the quality of life of residents living in long-term care. She does this by developing and coordinating relevant, timely, and practical tools and resources for long-term care homes, health planners, and academics. She is also the President of Artswell, a community arts charity that promotes wellness among vulnerable populations by using the arts. A graduate of the Ontario Institute for Studies in Education at the University of Toronto, Canada, in adult education and community development, Tracy brings the arts into everything she does.

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