Community engagement in a disengaged world: Developing and implementing educational workshops on deprescribing amid the COVID-19 pandemic

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Introduction

Science is seen as a rational activity. The *Cambridge Dictionary* defines science as "the careful study of the physical world, especially by watching, measuring and doing experiments and the development of theories to describe the results of these activities."[1] The *Stanford Encyclopedia of Philosophy* states that characteristic scientific activities include "systematic observation and experimentation, inductive and deductive reasoning and the formation and testing of hypotheses and theories."[2] We have an image of the cautious, skeptical, reasoning scientist, formulating hypotheses, collecting and pondering data and carrying out meticulous experimentation to produce incremental contributions to a vast web of scientific knowledge.

But science conjures up other images as well. We have the picture of Archimedes leaping from his bath with a joyful shout of "Eureka!" Bronowski has argued that science is an open-ended exploration that culminates in sudden explosions: "This is the act of creation, in which an original thought is born and it is the same act in original science and original art."[3]

Science is thus also a human endeavour, and as such, it is fraught with uncertainty and beset with human frailty. For example, commentators have recently become interested in the extent to which scientific investigations might be improperly swayed by the biases of investigators.[4,5] Moreover, scientists rely on their own cognitive abilities to carry out their reasoning, and in recent decades, we have learned about the surprising fallibility of human cognition, prey as it is to heuristics that afflict all people regardless of their intelligence or profession.[6,7]

This polarity—the effort to move forward calmly, rationally, with the incremental creation of reliable knowledge, proceeding apace with the inevitable limitations brought about by human frailty—has been evident over the past year during the global pandemic. We have all observed the daily drama of politicians and policy-makers trying to wring advice out of scientists and scientific panels and producing guidance and regulations that are by turns eagerly embraced, grudgingly accepted or robustly resisted by the public. By now most people have noticed that scientists themselves have been arguing with each other about the meaning of the emerging data and about the best way to move forward.[8,9]

Science lives at the ragged edges of uncertainty. We associate it with reason, method and truth, on the one hand, and also with intractable problems, confusion and uncertainty, on the other.

This polarity has been experienced by teams of scientists, like ours, whose slow, methodical movement forward as we implement a research agenda was profoundly disrupted by the pandemic. In this short article, we tell the tale of how our team of scientists balanced uncertainty and reason through the first months of the pandemic. In March 2020, we were working intently on our scientific question when sudden orders emanating from government authorities and research ethics boards brought our work to a halt. The boundaries between

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professional and personal concerns became blurred. A sense of powerlessness became evident. And yet we managed to regroup and persevere and brought our work to a conclusion in part by pulling our humanity—our concerns, worries and aspirations—more explicitly into the work.

First, we will briefly outline our scientific endeavour. Then we describe the disruption of the pandemic. Then we describe how we absorbed the shock, regrouped and carried on. Our task was to move a scientific discovery into the world, but as it happened, the world spoke back and rather sharply. We were reminded that our work is always in relationship with the situations and systems that engulf us.

Polypharmacy and the investigation of deprescribing

We are a team of pharmacists, scientists and research staff who work on the problem of polypharmacy among older people. Polypharmacy refers to using more medications than needed, especially where potential harm of the medication(s) may outweigh benefit. It has become a serious problem in Canada and elsewhere, especially in relation to older adults who often experience more than one serious health problem that might be mitigated by medications.[10-12]

Over the past decade, we have been trying to understand and ameliorate this problem. We started by creating evidence-based deprescribing guidelines to be used by physicians, pharmacists and other prescribers to help them make decisions about when and how to reduce medications safely to optimize patients' health outcomes.[13-17] Deprescribing is the planned and supervised process of reducing or stopping medications that are no longer needed or where harm may outweigh benefit.[18] As we implemented these guidelines, health care providers also told us that deprescribing would be facilitated if their patients came to them with questions about whether medications could be stopped. Following this advice, we went to members of the public and asked how we could support them in having these conversations with their providers.[19] They told us that they needed more information about their medications and ideas on how to talk with their health care providers; most felt they lacked the medication-related knowledge to have these conversations.[19] This feedback led us to expand our work into the area of public engagement and education. We began to work with a public advisory group to develop a series of in-person educational workshops that could help people to build skills needed to have worthwhile discussions with their physicians about the possibility of deprescribing some of their medications. We were all set to trial these workshops at a community centre in an Ontario town in the spring of 2020.

Our trajectory: The shock and absorbing the shock

In the late winter and early spring of 2020, our team was busily preparing to deliver a series of workshops. By February, we were hearing news of a new coronavirus and about a spreading wave of havoc, and on March 11, the World Health Organization (WHO) officially declared the coronavirus disease 2019 (COVID-19) outbreak to be a pandemic. But during this time, we were busy with our own work, with the research activities that brought us together and with our own teaching and clinical and committee work that filled our days. In our own ways, we all had a sense of foreboding, that "something wicked this way comes," but we were not at all clear about what was about to happen.[20]

The pandemic hit us at 8 a.m. eastern standard time on March 17, 2020, when Ontario Premier Doug Ford announced the provincial shutdown. Before the day's end, our plans and approaches were in disarray. It was not so much that one set of clear conditions was replaced by another. Instead, a reasonably coherent world vanished in a cloud of uncertainty.

We were carrying out funded research that was based on an agreement to produce specific results within clear timelines. All of this was suddenly in jeopardy. Would our funders be flexible? Or were they also in such disarray that we would receive no new instructions from them? How long would the lockdown last? What was going to happen to our employment?

Some of us had teaching and administrative responsibilities. Our students were confused and frightened, and our colleagues were hurriedly experimenting with unfamiliar technology. Some of us have small children, and unexpected arrangements had to be put in place. Some had older parents and news stories quickly gave rise to serious concerns about their health and safety.

Our project relied on the idea that through community engagement, we could bring about positive, generative change. By meeting with people, by interacting and gaining trust, by sharing worries and hopes and by providing guidance and information, we could help older adults to gain the confidence and knowledge needed to talk about their medications with their primary care providers. All of our experiences and research led us to believe that community engagement is best understood as a verb, as a series of human actions, with numerous people coming together to talk, confide, affirm and learn. We had imagined that we would be sitting with people in community lounges and meeting rooms, sharing experiences and discussing needs and finally, when we had succeeded in inviting the right people into the room and had accurately understood how best to support them, providing education and resources, coaching and encouragement, and this would contribute to a gradual change in the conversations between older people and their physicians.

Suddenly, none of this was possible. Face-to-face interaction was impossible. We found ourselves wondering if it would be possible to complete the project. We are a team of scientists distributed across 2 Canadian provinces and 4 institutions, so we were accustomed to holding meetings and working sessions on the telephone or on an Internet conferencing platform. But could the older adults we wanted to reach adapt to that world? The March 17 lockdown left us in the grip of uncertainty and doubt.

Trying out ideas and settling on a new course of action

It turned out, however, that this sense of uncertainty was not paralyzing. Although we experienced uncertainty, we also experienced a need to continue with our work. For the next 5 months, we went through a protracted period of experimentation and unease that, looking back, we came to call *the pivot*. We knew that our scientific enterprise was pivoting—it was changing and adapting, although what it was changing into was, for several months, unclear.

In some ways, we were stabilized by the norms and structures that we had created through several years of working together. We held our first team meeting in the conditions brought on by the pandemic on March 18, the day after the lockdown was declared. By this time, we already knew that the research ethics boards that governed our work had suspended all research activities involving contact with human subjects. During that March 18 meeting, we talked about our original intention to hold in-person workshops, and we discussed whether online workshops were a feasible mechanism for helping older people to gain confidence and skill in discussing medications with prescribers—and at that time, we were unsure of whether older people would be willing and able to interact on digital platforms. We also talked about delaying the in-person workshops until later in the year. And then, although we had no clear idea on how we would deliver the workshops, we spent considerable time discussing and refining the content of the workshops.

This, in fact, became characteristic of our approach over the next 5 months. We continued to hold our regular meetings. We produced agendas to guide our conversations during these meetings, and our research staff prepared meeting minutes that documented the highlights from our discussions and the actions that team members had agreed to undertake. This structuring of our work in the midst of uncertainty held us together and gave us some sense of continuity and familiarity as the world around us unfolded in unfamiliar ways.

In the spring and summer of 2020, team members did their best to manage feelings of loss, chaos, guilt and resignation. Some of us also, perhaps surprisingly, experienced a sense of relief as it became clear that we no longer needed to meet imminent and difficult commitments.

We experienced loss because the approaches and methods and some of the relationships that had been formed had to be set aside. We had already developed drafts of the materials needed to complete our work and were in the process of recruiting participants for our final workshops and now all of this had to stop. When we discussed the experience much later in the year, team members talked about the wrench being thrown into the works, about the world being overturned, about children suddenly bursting in upon meetings and work sessions and about the confusing sense of not knowing how to navigate through the stormy seas of the pandemic. Team members were also distracted by numerous other personal and professional responsibilities, which meant that many of us arrived for meetings feeling unprepared, inadequate and guilty.

Some of us have clinical responsibilities in community or hospital pharmacies and had to deal with worries that we should be spending more time on the frontlines of the pandemic, rather than safely meeting with our research colleagues. At times, there was even a sense of relief, as we considered shortcomings in the project and thought that the pandemic was freeing us from the need to expend time and energy to understand and repair those shortcomings. It became clear that COVID-19 did not allow for perfection, that we would need to accept the fact that our work was now beset by unaccustomed constraints and limitations. This was a difficult adjustment.

But at the same time, by meeting regularly and thus confirming our commitment to our work, we revisited and strengthened the bonds that held this team together. At a few meetings, 1 or 2 members opened up about their sense of discouragement and speculated that perhaps it was time to start withdrawing from the effort to solve the problem of polypharmacy. Through these discussions, we rediscovered the reasons why we had come together in the first place. Polypharmacy is not just a technical problem in need of calibration. It is also a human tragedy affecting thousands of lives. And our team had created enviable capacity and knowledge to take on this problem, to mobilize interest and cooperate with other similarly minded scientists around the world. We also had a chance to recall that we were held together by simple bonds of collegiality and friendship. We liked and respected each other. We had, in fact, become a little community in our own right, and despite the ravages of the pandemic, we were unwilling to allow these bonds to dissolve.

Looking back now, the spring and summer of 2020 was a long and painful pivot through which we tested the waters in an emerging online world and reimagined what community engagement might look like. Although in early spring, we assumed that the older Canadians with whom we wanted to engage would not be able to function in an online environment, by mid-summer, we had noticed that it had become routine for octogenarian grandparents to visit and play with their grandchildren on Zoom. As old techniques became untenable, new possibilities opened up.

We had decisions to make, plans to devise and new competencies to develop. Amending the ethics protocols again and again as our plans changed became a monumental task that was carried out by the research staff. Junior members of the team came to understand that others had confidence in them and were relying on them and felt empowered and motivated to seek out the knowledge and technology needed to connect with people effectively through virtual technology.

Completing the work

In early autumn, we came to a decision: our deprescribing workshops would be delivered virtually and we would make

no further efforts to engage in person-to-person interactions. The team's research staff prepared the final materials, including a workbook, handouts and slides, and the team met and finalized the materials. Participants were recruited. A series of 3 workshops were held, complete with interactive activities during the sessions and homework to be completed between workshops. Afterwards, we conducted a focus group to better understand how participants had experienced these events. We then finalized the "Talking about Your Medications" materials and posted them to the deprescribing.org website, so others could learn from and build on our efforts.[21]

The movement to reduce polypharmacy among older people and to develop and disseminate effective deprescribing practices is in its infancy. We began our work in 2012, and since that time, we have helped to create a global deprescribing movement that is characterized by launching new research projects to investigate deprescribing practices, developing evidence-based deprescribing guidelines to assist prescribers with specific classes of medication and ongoing efforts to raise awareness of and competence in deprescribing. For example, in 2018, we hosted an international symposium to report on research accomplishments and to encourage the formation of new collaborations to promote deprescribing.[22-24] If we examine this effort in relation to Rogers' diffusion of innovation theory, it may be reasonable to suggest that most of the "early adopters" are by now in the game and that we are starting to see an expansion of uptake by the "early majority."[25] Although the pandemic momentarily discouraged us and disrupted our work and contributed to lower participation rates in our workshops than we would have liked, we speculate that by forcing us to explore new ways of connecting with people and sharing our ideas, in the long run, our work may become more accessible and popular than would otherwise have been the case.

What we learned

Human beings are problem-solvers.[26,27] When we encounter, identify, try to understand and try to resolve a problem, we learn. The pandemic disrupted our reasonably orderly world and replaced it with a complex new environment through which we cautiously navigated. Here is a summary of what we learned.

In a complex and uncertain environment, planning is both necessary and futile

We needed plans, structures and clear intentions to drive our effort to understand and adapt to the unfamiliar circumstances of the pandemic and to complete our research project in a manner that met our obligations to the funder, provided value to participants and moved the deprescribing research agenda forward. We continued to hold our regular monthly meetings, assign action items and tend to our responsibilities. Most members of our team are pharmacists, and like many in this profession, we have a strong inclination to be conscientious and diligent in our work habits and to prefer stable working environments.[28] The pandemic tested us severely.

We need to be diligent in questioning our own assumptions

We had assumed that our work required face-to-face interaction and that older people might struggle to function comfortably or effectively in the context of web-based workshops. We were wrong. Although some of us still have a preference for collaboration and learning that occur when people meet together in the same physical space, we now acknowledge that people have the capacity to learn and become comfortable in virtual environments. And this applies to older adults. Given the shocking stories that arose in Canadian long-term care homes in 2020, a reckoning is under way about the latent ageism in how Canadians think about and treat our elderly.[29] We have learned a valuable lesson about human agency and resilience and believe that our work with older people will benefit from this lesson.

When uncertainty is unavoidable, resilience and adaptability are needed

As our detailed plans were disrupted, it became clear that it was counterproductive to put too much energy into creating a revised detailed plan. Instead, it became important to increase our capacity to adapt. Team members did this by investigating the principles, methods and technologies needed to support online collaboration and learning and by spending more time during meetings on open-ended brainstorming and personal check-ins that allowed for expressions of sympathy and support. We found ourselves developing more resilience, becoming more open to experimentation and observing the human milieu of our research environment with greater care.

Although initially we were trying to deliver a workshop that would be "good enough under the circumstances," it soon became apparent that our work was delivering unexpected benefits for our participants. The people who participated in our workshops were living lives of isolation that had been imposed upon them by the exigencies of the pandemic. They craved connection and interaction, and our work provided a venue that allowed people to come together, share ideas and experiences and support each other. Just as our team members derived unexpected benefits from participating in our regular online meetings, so too did our research participants benefit from the sense of connection and the interactions available through our workshops. We had designed many interactive components in our workshop because of the learning benefits associated with experiential pedagogy; we were surprised and delighted to learn that these activities also offered psychosocial benefits to the learners.

The pandemic also highlighted our own shared humanity. Although scientific research is a structured and rational activity, it almost always involves a step into the unknown. Scientists make good use of the words *control* and *confounding*, because both of these are prominent in our work. This tension between

method and uncertainty became prominent in 2020, and it provided a useful revelation for the younger members of our team. Our younger colleagues had harboured a sense that the experienced team members were brimming with confidence and certainty. The pandemic made it clear that we were alike in our struggle with the emerging challenges and uncertainties. This increased our sense of "being in it together" and encouraged us all to be forthright in sharing concerns and ideas.

The social capital we had created over several years of working together paid dividends

Together we brought perseverance and pragmatism to the work. We knew that addressing issues of polypharmacy through deprescribing remained vitally important and that the population we served—older adults and especially those experiencing frailty—were often suffering the most during the pandemic and would be in need of attention and support as the pandemic ended. Although our team's focus on polypharmacy was not directly implicated in the health issues central to the pandemic, we recognized that public awareness of the unique health needs of older adults was growing and that as the crisis waned, there might be a greater willingness to look at innovative ways of meeting those needs.

Our work frequently brings us in touch with people who have had a direct and, sometimes, sad experience of polypharmacy. Our shared professional commitments require that we do what we can to be helpful to the people we serve, and thus deprescribing has become both an intellectual pursuit and a moral imperative. During the pandemic, when the health system's attention has understandably narrowed to focus largely on COVID-19, Canada's frail elderly—especially those living in long-term care—have been exposed to risks and have suffered unacceptably. Our shared commitment to improving the lives of older adults through improved prescribing practices sustained us during the turbulent summer and fall of 2020.

Early in 2021, as we debriefed our experiences of the previous year, we realized that our scientific journey has always been a journey into the unknown and that this in fact is the very nature of the scientific enterprise. Polypharmacy is a complex social problem, and its amelioration calls for a complex and multifaceted response. The pandemic forced us out of our comfort zone, compelling us to be resourceful and creative as we found ways to complete our work. Our challenge now is to ensure that we retain and strengthen our new capacity for creative problem-solving.

Reflecting together on the meaning of our work

We brought our work on this project to a close by holding a meeting during which we shared recollections and learnings, relying on the technology of participation facilitation technique.[30,31] During this meeting, several of us commented on how the pandemic experience has highlighted the strong and enduring relationships we have forged through our shared enterprise. We recorded this session, and the result is a 32-page transcript of confusion, struggle, resilience and determination. By the end of the meeting, participants were making statements about what the project and the team had meant to them. One senior scientist said to the research staff, "You guys pulled this out and rocked it." Another said, "I am so grateful to be part of this group," and a third summed up their experience by saying, "I've been really, really blessed to work with a lot of really interested, passionate, motivated people."

We held this meeting for sharing reflections because of the intense experiences and feelings aroused by the pandemic. Afterward, several team members suggested that this reflective exercise ought to become a regular part of our work. After all, we do this work because it is important and because we find it meaningful. Sharing that meaning with each other strengthened our bonds and our commitment.

Conclusion

As we attempted to understand and make use of the power of community engagement in order to move our deprescribing program forward, we created and sustained an engaged community of researchers. We know that together with other scientists and teams around the world, we will mitigate the problem of polypharmacy.

Science has been described as rational, logical, objective, perhaps even unfeeling. We believe that science has a dual obligation: to pursue truth and to seek new ways to support the well-being of all. The rigour and discipline of science is necessary because of the contingencies and frailties of the human animal, and we help to overcome human limitations through the discoveries of science. ■

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