

**Practical Considerations for Conducting Research with
Marginalized Populations: A Case Study**

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Introduction

The past decade in Canada has seen a surge of interest from policy makers to the general public in dealing with complex and pressing social issues such as homelessness, mental health and addictions, and AIDS/HIV. Likewise, there is increasing eagerness -- and need -- by funding bodies and program providers alike to demonstrate program effectiveness. The nature of their problems, however, means that clients of such programs are often among the hardest-to-serve, and certainly even harder to engage in research. The purpose of this paper is to describe a program evaluation of a community mental health program in Ottawa, Ontario, which serves severely mentally ill homeless people. By focusing on both our successes and challenges in the implementation of this project, we hope to provide some direction for others who are about to engage in research with marginalized populations.

The study

This particular research project is being conducted jointly by the Ottawa branch of the Canadian Mental Health Association (CMHA), and the Center for Research on Community Services at the University of Ottawa. It is part of a broader, multi-site study -- the first of its kind in Canada -- funded by the Ontario Ministry of Health to evaluate the effectiveness of community mental health programs such as case management, as well as family self-help and consumer-survivor initiatives.

The program under study is CMHA's intensive case management (ICM) program, which provides individualized, long-term, practical support to people with severe and persistent mental illness who are homeless or at risk of becoming homeless. The study -- currently in its fifth and final year -- compares people who are receiving ICM services with those who don't; people in the latter group (also known as the control group) receive what is known as standard community care, which means they can apply for any other community service for which they are eligible. Participants in both groups are interviewed four times over two years, at baseline, nine, 18 and 24 months. It is expected that people who receive the long-term, intensive support will likely do better on a range of outcomes, including severity of symptoms, adaptation to the community, and quality of life.

Agency Interface

One of the most important practical considerations for conducting research with marginalized populations is to have a close, collaborative working relationship with those who are already providing services to the group involved. In our case, CMHA had been looking for some time for the means to demonstrate the effectiveness of its program, and already begun an association with a professor at the University of Ottawa's School of Psychology who had a research interest in mental health and homelessness. When the request for proposals (RFP) was issued by the provincial Ministry of Health, CMHA and the university established an advisory committee to develop a proposal, which was ultimately approved.

With a sense of shared history and mutual investment in the project, we were able to begin the evaluation process with a high level of trust already established between the parties, which paid off handsomely when challenges inevitably arose later on.

This background also illustrates another caveat for organizations about to embark on community-based research or program evaluation, which is to make a careful, realistic appraisal of one's capacity to conduct research. Program evaluation nearly always requires many more resources than is first anticipated, and usually, cannot simply be added on to someone's existing job responsibilities. Moreover, most organizations providing health or social services to marginalized populations are already over-burdened, either by the demand for services or insufficient funding, or by the job stress experienced by staff. If at all possible, we would recommend looking for outside resources to help with the evaluation or research project, particularly additional funding that acknowledges the extra workload of evaluation, and therefore minimizes the burden placed on existing staff resources.

Part of the appraisal of organizational capacity, of course, involves an assessment of the readiness of the program in question to be evaluated. We were lucky in this respect, in that CMHA already had a clearly articulated program logic model that spelled out program activities and functions, and linked these to desired goals. In addition, the agency had begun to develop a "research culture" within the organization, for example by including research and evaluation in its strategic plan. Understandably, this can be huge shift for organizations used primarily to delivering services, and it is not done overnight; even after several planning sessions with board and staff members regarding this new strategic direction, it would be fair to say that many staff members were less than thrilled with the increased requirements for data monitoring and reporting that ensued.

When it comes to dealing with obstacles to the research project, we have found it extremely helpful to have our research coordinator located at the agency. Being onsite has meant that she has been able to make the required connections between staff, interviewers, and participants, and ensure that questions or concerns about the project are dealt with promptly. As a result of her proximity and visibility, the research has become well integrated into the agency's operations, which in turn has increased staff ownership of the project. Without this close, collaborative working relationship between the researchers and agency staff, the project would no doubt have encountered more challenges along the way.

The participants

One of the most interesting aspects of this study has been the broad range of experiences and backgrounds of the participants. While certainly some of these would correspond to the popular stereotype of the homeless, many more do not: some people have been in the paid workforce at an earlier point in their lives,

some have been married and had children, some have had (and a few still maintain) close contact with their family of origin. Some of the participants have had extensive experience with the mental health system, while others have had virtually none. Roughly 20 percent of the participants are youth, aged 16-24 years.

What all participants in the study have in common, however, is the experience of coping with a severe and persistent mental illness - typically, a diagnosis of either schizophrenia or mood disorder -- that is significantly disabling and of long duration, often with a co-occurring substance abuse problem, and/or a history of physical or sexual abuse. Many have experienced long periods of homelessness or have a history of housing instability. Virtually all are currently single, unemployed, and receive social assistance; it is fair to say that virtually all struggle with social isolation, stigma, and crushing poverty.

To connect with this highly marginalized group of people, CMHA outreach workers engage people in the city's homeless shelters or on the streets, as well as receiving referrals from landlords, family members, and other agencies serving this population. Those whom outreach workers consider to be in need of long-term support and who meet eligibility requirements are referred to the ICM program, and it is at this point, during the recruitment phase of the study, that clients were approached to be part of the research.

Accommodation of participants' needs

Research methods must always be tailored to meet the needs of participants, but clearly, conducting research with such a disabled and marginalized group as described above requires special consideration. Assumptions about how one conducts research must be constantly reviewed, and careful planning and specific accommodations are required to ensure that the research goals are met and that the experience is a positive and empowering one for participants.

In this case, the obvious challenges concerned the severity of participants' psychiatric symptoms and the instability of their housing situations. It was less obvious, initially, how varied and unique each person's circumstances would be. Accommodations to meet people "where they were at" (both literally and figuratively) were numerous and covered many areas, as outlined in the following sections: the design of the research study, the measures used, procedures for recruiting participants and data collection, and even for data analysis. Some of these accommodations were predicted ahead of time and planned for, while others emerged as the study (and our learning) progressed.

Accommodations – Research Design

One of the most significant ways in which we adapted the design of the study to accommodate the needs of this client population was to include a provision for people who were in "exceptional circumstances". In our study, participants are randomly assigned to either the treatment or control group, allowing us to

definitively attribute any change in outcomes to the program, as opposed to other circumstances. Initial concerns about denial of treatment had been more or less addressed, after it was recognized that the need in the community was far greater than services could meet, so denial of treatment had always been implicit in the agency's process of taking on new clients. Not long after recruitment of participants had started, however, it became clear that some individuals were simply too disabled to participate in an interview, or even give informed consent. It was decided, therefore, that 20% of the openings for case management would be devoted to people in these exceptional circumstances, and that they would not participate in the research study per se.

This was a difficult decision. On the one hand, it demonstrated the researchers' understanding of the severity of clients' needs and sensitivity to staff concerns, and was crucial for generating and maintaining staff support for the project. On the other hand, the exceptional circumstances provision reduced our sample size and hence, the power of our analysis. It also means we cannot say that ours is a representative sample, and that our results can be generalized to the population of mentally ill homeless people as a whole. Much as we wanted to include everyone, we were not able to devise a way to obtain consent and collect the required data from CMHA's most disabled clients; the accommodations described in the rest of the article represent our best attempts.

We also found we had to adapt the research design by extending its timelines, especially for the recruitment period. Given that we would be doing research with homeless people, we knew from the start we would have to develop strategies for tracking and follow-up of participants. Fortunately, there is an increasing literature in this area, with many studies boasting retention rates of between 68 and 97 percent. We borrowed many of the ideas presented in other studies with the homeless, which we found to be very useful and would highly recommend, such as the use of incentives, getting permission from participants to contact their friends, family members and/or other professionals, and liaising with emergency shelters and lunch programs, etc. to find out if a given participant was still in touch, and to leave a message asking him or her to contact us.

Ironically, a lot of effort was spent in the early stages of the project to develop a protocol with the city's Social Services department for releasing – with the participant's consent, of course -- the address to which his or her social assistance cheque was being sent, yet in the end, we seldom relied on this. Usually, if a participant had moved, it was far afield – out of the region, province, or even the country. We found that our links with other community services were more helpful in determining if a given participant was still in town, and if so, how s/he could be contacted. As a result, we have been able to retain approximately 75% of participants in the study so far.

No matter how diligent the effort at tracking and follow-up, however, there will always be issues specific to marginalized populations that affect the timing of any

research contact, and overall attrition of participants. For example, with mortality rates twice that of the general population, any longitudinal research study involving the homeless is bound to have to deal with participants dying. Likewise, the rate of suicide amongst the severely mentally ill is much higher than average, and this too, has been something we have had to deal with. Researchers working with other marginalized groups such as injection drug users and people with AIDS or HIV, will have to take into account the norms and issues for their specific study population when planning follow-up, sample size, and overall timelines.

Accommodations - Measures

In choosing the measures or sets of questions for our study, we were guided by what is known about best practices in case management, as well as by the goals of the ICM program for improvements in clients' psycho-social functioning and quality of life. On this basis, we wanted to reflect everything that could make a difference in people's lives. On the other hand, we were concerned about the length of the interview, particularly for people who were bothered by very troublesome symptoms.

We chose measures that would be as clear and relevant for the participants as possible, but not all were perfectly suited to our study population. The Drug Abuse Screening Test (DAST), for example, interchanges the words "drug use" with "drug abuse". While the instructions for the measure state that prescription drug use should be discounted, many of our participants described themselves as feeling more ambivalent about having to rely on psychotropic medication than on medication for a physical condition. From this perspective, questions such as "Do you ever feel bad about your drug use?" can be confusing or even mildly offensive. Moreover, altering a scale is not always an option, since this can affect its validity and reliability. In the end, it may be better to stick with a less-than-ideal measure, but anticipate the likely ways it may be interpreted by one's respondents.

In some cases, however, we did choose to adapt the measures slightly to make them easier to use. For example, we developed an interview version of the Multnomah Community Ability Scale (MCAS) to use with people who were no longer receiving services from a CMHA worker, and for whom we had no other means of making obtaining an assessment (+Note: an interview version is now available from the authors of the MCAS). To accommodate those with literacy problems, we added smiley faces to some of the response cards to make them easier to understand.

Sometimes, however, our assumptions about participants' needs vis a vis the measures didn't hold true. In the above example, it turns out that for every person who appreciated the smiley faces, there were two more who were offended, and said they felt patronized by them (we quickly learned to have two sets of cards handy). Another example concerns the Brief Psychiatric Rating Scale (BPRS), which we had initially resisted using for fear that it would come

across as too “clinical” compared to the rest of the interview, which focused on community functioning. We also feared that, as a result, it might erode the rapport we hoped would develop between participant and interviewer. In the end, we agreed to include it so that we could most accurately compare the symptoms experienced by our study participants with those of the other programs in the multi-site study, but we elected to use the 18-item version instead of the longer version used by the other sites.

Ironically, we have found that, far from being too clinical, the BPRS is one of the more successful parts of the interview. For one thing, the response options are not structured, so that it turns into more of a conversation. For another, the topic is the participant’s recent experience of psychiatric symptoms, an area in which the participant is the ultimate expert. Most people seem to enjoy the opportunity to talk in detail about something that, for many, is an integral part of their daily lives. Some of those who have had contact with the formal mental health system have even been through this type of clinical assessment before, and seem to enjoy the opportunity to demonstrate their experience, even if they regard some of the questions as slightly ridiculous because they are not personally relevant, such as those about delusions or hallucinations.

Finally, the results of our pilot-testing (which we found to be a crucial phase) encouraged us to add some open-ended questions to the interview to help participants with the interview process. One of the key measures in the interview is the Satisfaction With Life Scale, and though brief, the questions ask the participant to reflect on his or her life in a summative fashion, and compare it with his or her personal ideal. We found that, for those who have encountered great difficulties in their lives, and have had to postpone or give up on hopes and dreams, this reflection can be a pretty demoralizing experience. We quickly realized we needed to find a way for the interviewers to support participants through that experience, and so added the open-ended question, “How do you cope with the rough times?” We also trained the interviewers to be alert to signs that participants might need further support after the interview, but for the most part, have found this to be unnecessary. People seem to appreciate the implicit acknowledgement that they are, in fact, coping (and have usually been doing so for a long time), and to share the rich variety of methods – both positive and negative – they have developed to deal with their difficulties.

Accommodations - Procedures

With the accumulated experience of community mental health and social services for the homeless mentally ill and other marginalized groups, it is generally accepted that one has to provide services “in situ”, in other words, to engage people on their own turf, whether that be at emergency shelters, soup-kitchens, drop-ins and day programs, sometimes even on the streets and under bridges.

The same assumption is true for research in community settings. In the recruitment phase of the project, research staff would go out with an outreach worker to all kinds of settings to meet clients to talk with them about the research project, and hopefully, obtain their consent to participate. Sometimes the meeting would be set up in advance, but often not; even if it had been, it was often necessary to drive or walk around the downtown area in search of the client. Sometimes, however, we were surprised by where we ended up, and at how unorthodox the methods we had to use to find people. On one occasion, a researcher went out with an outreach worker to meet a particularly reclusive client who lived out-of-doors on a vacant lot. After approaching his “hang-out” and seeing his various clothing and possessions strewn over the bushes, the two set about beating the bushes (literally!) to see if he was there and willing to be approached.

As this example shows, engagement of marginalized populations in research – as with service provision – requires the researcher to be flexible and open-minded about when, where and how to engage with prospective participants. To these qualities we would add persistence and sensitivity. We found that in a few cases, clients found it so difficult to meet new people and process new information that it could take several meetings before he or she was ready to discuss participation in the project, let alone give informed consent

We also found that the recruitment process was a delicate balance of providing a client with the information s/he needed to give informed consent, while at the same time gauging the person’s readiness to hear that information, to avoid a premature refusal. This was important; refusal at this stage meant that the individual would not be eligible for CMHA’s ICM service for two years. Clearly, we as researchers had to respect each person’s right to refuse to participate, but we also felt obligated to ensure that, as much as possible, the refusal was also a fully informed decision. In the end, we found this process required quite a sophisticated skill set, and had to centralize recruitment responsibilities to the two researchers who were most successful engaging with clients.

Similarly, interviewing such a marginalized and disabled group of people requires a very specialized and complex set of skills. It would not be an overstatement to say that the quality of our interviewers has been the key factor in the success of the study so far. Beyond the technical capacity to administer the interview protocol properly, we found that the most successful interviewers are those who are interested in and comfortable meeting people from very different circumstances from their own, and who have the sensitivity to ensure that people feel respected and truly heard. Interviewers must know how to adapt their energy level and presentation so as not to overwhelm a participant, especially one who is severely depressed. Assessment skills are crucial, and not just in a clinical sense; it is the interviewer’s job to decide if a participant is too inebriated or too symptomatic to participate in the interview that day, or if a participant is becoming too fatigued and needs a break, or to continue the interview the next day.

Throughout the interview, the interviewer must be alert as to what impact the questions are having on the participant, so that interpretations are consistent, assessments are made properly, and supports can be put in place after the interview, if necessary. We found it worth the effort to match interviewers to participants on the basis of personality and the skills of the interviewer.

In our study, interviews are generally conducted in the community in semi-public settings such as offices in drop-in centers or shelters, or at the university, local libraries, or even restaurants. We try to choose locales that are familiar to participants and in which they feel at ease, and to balance the need for privacy with that of safety for the interviewers. As such, interviews are seldom conducted in participants' homes, and not without two interviewers present. If anything, we have become stricter about this as time has progressed; even as research staff members come to know participants better, we realize we do not always have sufficient knowledge about where and with whom participants live. We found it has been critical for the research coordinator to work closely with agency staff to be up-to-date on participants' status, and to generally be cautious in assessing potential safety risks.

In order to help interviewers know how best to accommodate participants' needs during data collection, we have provided extensive and ongoing training. As post-graduate students in clinical-community psychology, most have the clinical knowledge and skill required to recognize and accommodate most mental health issues that may be experienced by participants during the course of an interview. What has initially been lacking, for most, is an understanding of what it is like to be homeless, such as the daily challenge of getting enough sleep and having to walk all over town for meals, appointments, and shelter. Our training curriculum explores these issues – and their behavioural implications – in detail, and gives practical advice on how to create a calm, relaxing & successful interview experience for participants.

We have also had to provide specific training and a protocol for suicide risk assessment and intervention. In fact, we have been somewhat surprised by the frequency with which some participants disclose (unprompted) thoughts and experiences regarding suicide. As a result, we have adapted our "scripts" at the informed consent and interview stages to qualify our assurance of confidentiality, so that participants understand the interviewer's obligation to inform the research coordinator or agency staff if s/he feels there is even a moderate risk for the participant (the coordinator, in turn, liaises with staff at the appropriate agency for intervention, if necessary).

On a more general level, we have allocated more of the research coordinator's time for debriefing and support for the interviewers. This is particularly important after a difficult interview; interviewers have had to deal with quite a range of challenging content and behaviours, such as from the participant who only wanted to discuss his role in the coming apocalypse. Even if the interview had

gone reasonably well, however, interviewers would sometimes feel overwhelmed by the complexity and severity of people's illnesses, and the lack of simple solutions for their difficulties. It has been important for us to recognize that the interviewers work pretty much in isolation, and sometimes – like those who work in direct service – experience role strain that requires them to share their experiences with someone else who is familiar with the participant.

Last but not least, we have tried to accommodate participants' (sometimes very basic) needs with incentives for participation. Interviewers pay participants an honorarium of \$20 for each completed interview, a process approved by the university's ethics committee, and endorsed by CMHA. On rare occasions when a participant objects to the honorarium, we have tried to find another acceptable means to acknowledge their participation, such as the time we bought cat food for a man who tended a herd of wild cats. In addition, interviewers often buy juice or coffee for participants, and from time to time, lunch or breakfast, if the person is in particularly dire straits. We sometimes purposely arrange for the interview to be held near the end of the month, when the honorarium will help bridge the gap until the next social assistance cheque arrives. Conversely, we avoid scheduling interviews at cheque time for participants whom we know to have problems with substance abuse.

There is no question that, for someone in dire poverty, even \$20 can be a powerful incentive. There is always a tension between what constitutes remuneration and what is coercion, and this will vary according to the circumstances of the population involved. In our case, our participants are all homeless, living in poverty. We cannot ask them to complete an interview if they are hungry, and it seems unreasonable not to acknowledge their time, trouble, and expertise in a way they find meaningful. Other groups will have to come to their own decisions on their policy in this area.

Accommodations – Analysis Stage

Now that we have begun the process of data analysis, there are additional data we wish we had collected, that would better describe the circumstances of participants' lives. In hindsight, we wish we had used the 24-item version of the Brief Symptom Rating Scale (BPRS), since it would have helped us make a more complete assessment of symptoms and would only have added about five more minutes to the interview. We also wish we had asked if participants had a history of sexual abuse; from the literature and what some participants have disclosed, this appears to be a significant issue for a large number of people in our study population (and no doubt in other marginalized groups), yet we have no systematic way of determining this. On the other hand, the very sensitive nature of the subject requires careful consideration of when and how the question is asked, and by whom.

Finally, we have realized that even the most flexible and accommodating of research designs does not fit everyone. In our case, there are a few participants in the treatment group who, for a variety of reasons, are not receiving much in the way of treatment. They refuse or avoid contact with their workers, either because their psychiatric symptoms are so debilitating or because they have lived in isolation for so long that social contact is difficult. Even beyond these unusual examples, however, we have found there is a huge variation in the amount and type of service received by participants in both the treatment and control groups, whether it be due to client factors, staffing issues, or more systemic service delivery issues, such as an overlap in services. Regardless of the reason, we have to find a means of describing the intensity of service after-the-fact, so as to provide a context for the changes (or lack of them) in client outcomes. In other words, we have to change the way we do our analysis because the way in which people live their lives and receive services does not neatly fit into our assumptions about service delivery and our research model.

Conclusion

We have certainly learned as much from our mistakes on this project as from our successes. In the process, we have also made some pleasant discoveries.

For one thing, everyone involved in the project – including the researchers – was initially very skeptical that participants would be able to sit through the entire interview, and we felt we had to be careful not to over-tax participants' energy levels and attention spans. We have found, however, that our interview protocol takes less time to complete than first anticipated (on average, an hour and a half), and while fatigue is certainly an issue for many participants, this is usually easily dealt with by paying attention to pacing, suggesting breaks, or doing the interview in two parts. We have been particularly surprised by how well people with very challenging symptoms have managed the interview. Even people who experience persistent and intrusive voices, for example, have been able to attend reasonably well to the interview for a period of time, although it is clear that this takes a significant effort. The surprise is that they have been willing to make the effort, and not once, but several times.

In fact, we have been pleasantly surprised at how positive the majority of participants say they found the process. At the end of the final interview at 24 months, we ask each participant a set of questions about the experience of being in the research project, and why they continued with it once they had started. Not surprisingly, many people have mentioned how much they appreciated the honoraria, but most go on to say how much they have benefited from the process. As one person said, "it's good, it makes you think about things. I should think about this stuff more often". Many speak of appreciating the opportunity to contribute, especially to share their experiences in the hope that it will be used to help others. Many participants seem to derive a sense of usefulness, or purpose, that is missing from their daily lives.

Another aspect of the study participants say they enjoy is the social contact with the interviewers. We had initially hoped that each participant would see the same interviewer over the course of his or her two years in the study, but this has not always been possible. Even when this has not worked out, many participants report how much they've appreciated the chance to talk with someone about their experiences. There are those who particularly appreciate the chance to talk with someone outside of their usual circle of acquaintances; one man said, "I don't get much of a chance to chat with a pleasant young lady anymore; it's quite a big deal for me". Even more important, however, seems to be the genuine interest demonstrated by the interviewers in participants' experiences, and the fact that participants get to talk about their lives in some depth, sometimes more so than with their case workers.

In fact, the extent to which participants are willing to discuss even very personal aspects of their lives has been quite remarkable, and somewhat humbling for the interviewers. Part of this may be that people find it easier to open up to someone who is not an ongoing part of their lives. More than this, though, we have come to realize that, like any marginalized group, there are very few participants who have an opportunity to sit and tell their story to someone who shows respect and genuine interest. Likewise, it is a very powerful experience to be the interviewer and have someone list you as a significant person in his or her social network inventory, particularly when you only see the person every nine months or so.

Finally, our interviewers keep telling us how much they have learned from this project, and not only because they have a chance to receive clinical training that would not otherwise be available to them i.e., with severe and persistent mental illness. They too, report being pleasantly surprised by how much they have enjoyed meeting with participants, and at how engaging and interesting they have found the client population. We think this hits on one of the most valuable aspects of working with marginalized populations; as with anyone, meeting new people and learning about their lives is an enriching experience. That one has an opportunity to get past common stereotypes and misperceptions is an added blessing. The challenge, then, is to take that experience and make it of equal value to the people involved in one's research; to provide substantial and tangible benefit for the participants -- not just for the period of the study, but afterward as well.

For more information about this project and the CMHEI Multi-site study as a whole, please visit <http://www.ontario.cmha.ca/cmhei>