CONDUCTING EVALUATION RESEARCH WITH HARD-TO-FOLLOW POPULATIONS: ADOPTING A PARTICIPANT-CENTRED APPROACH TO MAXIMIZE PARTICIPANT RETENTION

Heather Smith Fowler
Tim Aubry
Centre for Research on Community Services
& School of Psychology, University of Ottawa
Ottawa, Ontario

Marnie Smith
Canadian Mental Health Association, Ottawa Branch
Ottawa, Ontario

Abstract: Longitudinal designs are effective for the evaluation of innovative social programs, but attrition can be a significant problem, particularly with hard-to-follow populations such as persons who are homeless. Tracking strategies for locating participants are essential, but retaining participants requires anticipating and addressing participants' needs at every stage of the research. A strategy that emphasizes appropriate interviewer characteristics, the relationship between interviewer and participant, and participants' "investment" in the research is critical. In other words, evaluation researchers can improve the retention of even hard-to-follow study participants by adapting research design and procedures to be "participant-centred." An example is given of a program evaluation in Ottawa, Ontario, that implemented strategies to adapt to the needs of persons with severe mental illness and a history of homelessness.

Résumé: Bien qu'ils s'avèrent efficaces pour évaluer les innovations sociales, les devis longitudinaux présentent un défi considérable à cause du phénomène d'attrition. Ceci est d'autant plus vrai lorsque la population visée par l'étude est marginalisée, comme c'est le cas pour les sans-abri. Des stratégies pour suivre leurs déplacements sont indispensables, mais pour maintenir leur participation, il faut anticiper leurs besoins et trouver une façon d'y répondre. Des stratégies mettant l'accent sur les carac-

Corresponding author: Heather Smith Fowler, Manager, Women's Health Research Unit, University of Ottawa, 228-1 Stewart Street, Ottawa, ON K1N 6N5; <hsfowler@uottawa.ca>

téristiques des interviewers, de bonnes relations entre les interviewers et les participants, et l'engagement des participants dans la recherche sont recommandées. En d'autres mots, les évaluateurs peuvent maintenir un taux de participation plus élevé dans une étude longitudinale en implantant une approche centrée sur les participants. Un exemple d'une étude qui utilisé ces stratégies avec des personnes atteintes de troubles mentaux sévères et persistants et une histoire d'itinérance est présenté.

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. Likewise, there is increasing need for funding bodies and program providers alike to demonstrate the effectiveness of innovative social service programs (Dennis, Buckner, Lipton, & Levine, 1991). Longitudinal research using true experimental or quasi-experimental designs offer the most compelling means of providing such evidence (Menard, 1991; Shadish, Cook, & Campbell, 2002), particularly since the nature of these conditions is such that people often experience variations in their functioning over time (Susser, Goldfinger, & White, 1990).

The nature of homelessness, mental illness, and addictions also means that clients of such programs are among the hardest to serve, and certainly even harder to engage and retain in research (McKenzie, Peterson Tulsky, Long, Chesney, & Moss, 1999). Similarly, studies with runaway and high-risk youth, battered women, and people with HIV/AIDS, among others, must contend with participants who may be highly mobile, purposely trying to remain anonymous, and/or more concerned with safety and survival than research. For those who conduct longitudinal evaluation research with such populations, minimizing attrition is one of the most serious challenges (Morrissey & Dennis, 1990).

Consequently, a relatively new literature on methods for tracking and follow-up with hard-to-locate populations has emerged (Desmond, Maddox, Johnson, & Confer, 1995; McKenzie et al., 1999; Ribisl et al., 1996). A review of this literature reveals a wide array of strategies, the most common of which are specific techniques for tracking and locating participants. Many of these tracking techniques are now routine in longitudinal evaluation research, such as asking participants for comprehensive contact information at baseline, using the same researcher to track a person over time, and providing

participants with a telephone number to contact researchers in the event of a change of address or telephone number (McKenzie et al., 1999).

Also frequently cited are "collateral" tracking techniques such as release forms, contacts with participants' friends and families, and arrangements with social services and other agencies (e.g., Aubry, Klodawsky, Hay, Nemiroff, & Hymans, 2004; Bootsmiller et al., 1998; Dilonardo, Kendrick, & Vivaldi, 1993). Some techniques are remarkably creative, such as offering a finder's fee to friends and family members (e.g., Bootsmiller et al., 1998; Cottler, Compton, Ben-Abdallah, Horne, & Claverie, 1996), holding a party for youth previously lost-to-follow-up (Gwadz & Rotherman-Borus, 1992), using photographs of participants (Belcher & Toomey, 1988), or contacting participants via the World Wide Web (Passetti, Godley, Scott, & Siekmann, 2000) or e-mail (Aubry et al., 2004).

Not surprisingly, tenacity and creativity are frequently identified as among the most important elements of a successful tracking system. Ribisl et al. (1996), for example, recommend techniques used by private investigators for locating missing persons (e.g., Gunderson & McGovern, 1989), including the use of such as national databases as the Reverse Telephone Directory in the United States. As Desmond et al. (1995) put it, "patience, persistence, time and travel" are required, whether it be locating children with ADHD (Hartsough, Babinski, & Lambert, 1996), battered women (Rumptz, Sullivan, Davidson, & Basta, 1991), substance abusers (Cottler et al., 1996), or injured trauma survivors (Rajotte, Fuchs, & Zatzick, 2003).

Many of the strategies identified in this literature, however, are not so much tracking techniques as *retention strategies*, in that they focus on ways to engage and sustain participants' interest in the research and in ongoing participation. Essentially, their goal is to make participation "enjoyable and effortless" for participants (Bootsmiller et al., 1998, p. 2678), and "convenient and rewarding" (Ribisl et al., 1996, p. 9), by reducing the obstacles or "costs" of participation and maximizing the rewards. In so doing, retention strategies generally focus on either (a) the characteristics of the researchers, (b) the relationship between interviewer and participant, or (c) ways to increase participants' motivation to follow up.

The most commonly cited motivational techniques are financial incentives, whether in the form of cash, gift certificates, meal vouch-

ers, or even a cash prize lottery (e.g., Gwadz & Rotherman-Borus, 1992). Some researchers have found it useful to increase the amount of payment for subsequent interviews to encourage follow-up (e.g., Rumptz et al., 1991; Toro et al., 1997). The use of financial incentives must obviously be appropriate for the population involved, in that they are not perceived as coercive or contributing to a problem such as existing substance abuse. Ideally, they should be "part of an overall plan that include[s] interventions, referrals, advocacy, or education and addresse[s] the substantive concerns of the participants" (McKenzie et al., 1999, p. 419).

Non-tangible rewards can be almost as powerful as financial incentives. It is no coincidence that hard-to-follow populations are generally marginalized and living in poverty, so providing meals, transportation (either directly or by providing bus tickets or taxi chits), or childcare is nearly always appreciated. Here, too, the most successful alternative incentives take into account the specific needs of the study population; in Woody, Metzger, and Mulvaney's (1994) study of AIDS vaccine trials for injection drug users, participants were offered education and counselling services, free condoms, and bleach kits. Likewise, a study by Cohen et al. (1993) on the effectiveness of a linkage program for mentally ill homeless persons emphasizes the importance of using whatever incentives are meaningful to participants. These authors cite the example of one of their researchers with a law degree who provided informal legal assistance to a participant as a means of building rapport.

The most powerful incentive, however, is often the relationship established between interviewer and participant. Effective means of building rapport include holding the interview in a location convenient for (or chosen by) the participant, informally chatting with a participant before the start of the interview, conducting the interview at an appropriate pace, and demonstrating respect and active listening. After the initial interview, some researchers have tried to maintain rapport by sending reminder calls and letters to participants, or even birthday and Christmas cards (e.g., Bootsmiller et al., 1998). While researchers must be careful to maintain a professional role and ensure similar administration of measures, most reports of research with hard-to-follow populations indicate that enhancing interviewers' personal contact and involvement with participants yields greater benefits in terms of study retention because participants find the process more fulfilling (McKenzie et al., 1999; Ribisl et al., 1996). As Bootsmiller et al. (1998) found in their evaluation of an innovative dual diagnosis treatment program, partici-

pants were primarily motivated to participate not by money, but by being able to talk to someone about their problems, and by the interviewer's "caring attitude and companionship" (p. 2679).

Given the importance of the research relationship in retaining participant involvement, interviewer skills and characteristics are paramount. According to Cohen et al. (1993), the "[p]ersonal resources of research assistants make a distinct contribution to interview success" (p. 350). Curiously, this is an area to which little attention is paid in the literature, except in terms of demographic characteristics, and this in the absence of consensus that these characteristics must necessarily match those of the population being studied (Ribisl et al., 1996). Researchers generally cite the importance of having "quality" staff members who are "culturally competent" (Katz et al., 2001) in terms of their comfort with the study population and their knowledge of the cultural, social, and economic issues faced by participants (McKenzie et al., 1999). As Gwadz and Rotherman-Borus (1992) report, "[w]e hired interviewers who were friendly, ethical, likeable, as well as attentive to detail…, interpersonally attractive people with whom the youths would feel comfortable" (p. 73).

The common element of these retention strategies is the emphasis on cultural and inter-personal sensitivity to the participants, their needs and circumstances. We contend that one of the keys to conducting research with hard-to-follow populations is ensuring that the needs of participants stay central to the study. Rumptz et al. (1991) call it "an ecological approach" that does not burden the participant; Gondolf (2000) refers to the importance of addressing "human subject issues" such as maintaining victim safety and developing tracking procedures that are sensitive to the study population (in that case, by not making victims of male batterers feel "stalked"). However, we prefer the terminology used by Rajotte et al. (2003) in describing their longitudinal research with injured trauma survivors: they cite the importance of patient "centeredness," of having the study design and research protocols organized to meet participants' needs, which in turn optimizes follow-up. In our experience, even hard-to-follow study populations will remain involved in research projects if participants feel rewarded by and invested in them, that is, if their needs are treated as being equally important as those of the research project.

We present the following description of an evaluation that made a variety of accommodations to meet the needs of a hard-to-serve study population, namely, people with psychiatric disabilities and a history of homelessness. Accommodations were numerous and covered many

areas: the research design, the measures used, and the procedures for recruiting participants and for data collection. However, our study does not pretend to be exemplary in its focus on participants' needs, nor did it use a participatory-action research model, which could arguably be considered the epitome of participant-centredness, whereby all aspects of the research are articulated and decided upon by participants themselves (Cousins & Whitmore, 1998). Rather, we present this as a case study of lessons learned about how one can successfully retain challenging research populations by accommodating their needs. In our case, some of these accommodations were predicted ahead of time and planned for, while others emerged as the study (and our learning) progressed. By focusing on both our successes and mistakes in the implementation of our evaluation, we hope to provide some guidance for others who are about to engage in similar research with marginalized and hard-to-follow populations.

THE STUDY

This research project was conducted jointly by the Ottawa Branch of the Canadian Mental Health Association (CMHA) and the Centre for Research on Community Services (CRCS) at the University of Ottawa. It was part of a broader, multi-site study called the Community Mental Health Evaluation Initiative (CMHEI), funded by the Ontario Ministry of Health to evaluate the effectiveness of community mental health programs such as case management and crisis intervention, as well as family self-help and consumer-survivor initiatives. The program under study was 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.

PARTICIPANTS

We knew from the onset that implementing this research would be challenging, primarily due to the severity of participants' mental illness and the instability of their housing situations. Nevertheless, we were surprised to discover the broad range of experiences and backgrounds of the participants. While certainly some of these would correspond to popular stereotypes of the homeless, many more did not. For example, of the initial sample of 147 participants (i.e., those who completed the first interview), just over a quarter were currently employed (27%, mostly in volunteer or casual positions), yet well over 80% had been in the paid workforce at an earlier point in

their lives, including several people who had worked in the government sector. While only one participant was married at the time of the first interview, over one-quarter (29%) had previously been married; many of these mentioned that they had had children, and a few were still in close contact with their family of origin.

However, all participants shared the common experience of coping with a severe and persistent mental illness — typically, a diagnosis of either schizophrenia (48%) or affective disorder (52%) — that was significantly disabling and of long duration, often with other complex needs such as a co-occurring substance abuse problem (28%). Many had experienced long periods of homelessness or housing instability, and all were either currently homeless or at significant risk of becoming homeless. Virtually all were single at the time of the study (96%), unemployed (88%), and receiving social assistance; it is fair to say that virtually all struggled 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 through referrals from landlords, family members, and other agencies serving this population. Those whom outreach workers consider in need of long-term support and who meet eligibility requirements are referred to the ICM program, and it was at this point that clients were approached to be part of the research. If agreeable, they were matched with another study participant on the basis of age (youth or adult), gender, and level of functioning, and were then randomly assigned to either the treatment (ICM) or the control condition. In our study, the control condition was considered standard care (i.e., whatever other services were available in the community other than CMHA's ICM program). Participants in both groups were interviewed four times over two years; at study entry and at 9, 18, and 24 months' follow-up.

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." Agency staff had initially been concerned that random assignment of participants would deny treatment to those in need, but

the researchers pointed out that even the agency's existing intake procedures denied treatment to large numbers of applicants, as is always the case when community need exceeds the supply of services. More important to the University Research Ethics Board was the fact that the effectiveness of the intervention (i.e., intensive case management) with the targeted population had not yet been demonstrated, and similar alternative services could be accessed elsewhere in the community. Not long after recruitment had started, however, it became clear that a small number of individuals were simply too disabled or too overwhelmed by crises at the time to participate in an interview, or even to 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 decision was difficult, and had important implications for the study. On the one hand, it demonstrated the researchers' understanding of the severity of clients' needs and their 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. Moreover, by not including CMHA's most disabled clients, it limited the representativeness of the study's findings.

We also found that we had to adapt the research design by extending its timelines, especially for the recruitment period. Although we had planned to over-sample participants to minimize the impact of attrition, we could recruit only as quickly as new clients came into the program. As a result, our recruitment period was one year longer than anticipated. Our procedures for tracking and follow-up of participants also evolved over the course of the study, and we borrowed many of the useful ideas presented in other studies with the homeless, such as the use of incentives, getting permission from participants to contact friends, family members, and service providers, and leaving "please contact us" messages with local emergency shelters and lunch programs, etc. As recommended by Ribisl et al. (1996), we found it helpful to customize tracking efforts, based on what we had learned about participants' circumstances and preferences. For example, while we found it effective to mail letters to participants who didn't have telephones, we refrained from sending mail to more than one participant who was highly suspicious.

In other cases, our initial assumptions about how best to locate our study population were disproved, and we had to adapt our tracking

methods to find participants. In the early stages of the project, for example, we developed a protocol with the City of Ottawa's Social Services Department for releasing — with the participant's written consent — the address to which his or her social assistance cheque was being sent. In the end, however, we seldom used this method to locate people. While others have found such collateral techniques helpful to locate transient populations such as the homeless (Aubry et al., 2004), it was our experience that if a participant moved, it was usually far afield — out of the region, the province, or even the country. Like Bootsmiller et al. (1998) and others, we found that our informal relationships with other community services were more helpful in determining whether or not a given participant was still in town, and if so, how s/he could be contacted. In the end, we were able to retain approximately 70% of participants in the study, an attrition rate which, while not stellar, compares favourably with that of other research with hard-to-follow populations (see McKenzie et al., 1999; Ribisl et al., 1996; Toro et al., 1997).

No matter how diligent the effort at tracking and follow-up, however, there will always be issues specific to hard-to-follow populations that affect the timing of any research contact and overall attrition of participants. For example, with mortality rates 2 to 30 times that of the general population (Cheung & Hwang, 2004; Hwang, 2000), any longitudinal research study involving the homeless must contend with some participants dying. In particular, the rate of suicide amongst the severely mentally ill is much higher than average (Hiroeh, Appleby, Mortensen, & Dunn, 2001). In our study, six participants died, including three by suicide. Aside from the personal devastation of these deaths for friends, family, agency staff, and even researchers, these losses affected our level of attrition and our paired matching process. In other cases, we adjusted the timing of our data collection or cancelled interviews altogether because participants were dying or were themselves grieving the deaths of friends or family members.

Measures

In choosing measures for examining client outcomes, we were guided by previous research on case management, as well as by the goals of this particular ICM program for improvements in clients' psychosocial functioning and quality of life. Specifically, we wanted to examine the range of outcomes on which participants could experience positive changes. This comprehensiveness needed to be balanced with finding a manageable length of interview for people bothered by very troublesome symptoms.

We chose measures we thought would be as clear and relevant for participants as possible, but not all proved suitable for every participant. For example, the Drug Abuse Screening Test (DAST; Skinner, 1982) interchanges the words "drug use" with "drug abuse." While the instructions for the measure state that the normal consumption of prescribed medication is not considered problematic, many of our participants said they felt ambivalent about having to rely on psychotropic medication. From this perspective, questions such as "Do you ever feel bad about your drug use?" can be confusing or off-putting, evoking responses consistent with drug abuse. Other participants with strong opinions about drug abstinence resented being asked 20 questions that appeared to presume drug use.

In response to such concerns, we chose to make minor changes to a few measures, such as adding skip instructions to the DAST, which we felt still captured the incidence and extent of drug use. Specifically, if the responses to the first two questions indicated no consumption of illegal drugs or abuse of prescription drugs in the specified time period, interviewers were instructed to skip to the last five questions, and to score the skipped items consistent with no abuse. In so doing, we were conscious of the potential risks to instrument validity and reliability, but balanced this with the need not to alienate many of our participants. Moreover, we were guided in our choice of questions by a shorter version of the DAST by the same author.

Other changes to our measures included the addition of stickers to some response cards, to accommodate those with literacy problems. We also developed a client interview version of the Multnomah Community Ability Scale (MCAS; Barker, Barron, McFarland, & Bigelow, 1994) to use with participants who were no longer receiving services from CMHA. Typically, the MCAS is completed by a service provider who is knowledgeable about the client. However, when participants (primarily in the control group) were no longer receiving services, MCAS ratings were made by the interviewers based on information they collected directly from participants.

Sometimes, however, our assumptions about participants' needs vis-à-vis the measures didn't hold true. For every person who appreciated the above-mentioned stickers, there were two who were offended (we quickly learned to have two sets of cards handy). We also had hesitated to use the Brief Psychiatric Rating Scale (BPRS; Overall & Gorham, 1962), for fear it would be perceived by participants as too "clinical" compared to the rest of the interview, which focused

on community functioning. Although we eventually included it in our interview protocol to facilitate comparisons with other CMHEI programs, we elected to use the shorter, 18-item version. Yet far from being too clinical, the BPRS was one of the most successful parts of the interview. We believe this was due to the open-ended, conversational format of the BPRS, in which interviewers rate the severity of participants' symptoms based on their descriptions of them. We found that most people seemed to enjoy the opportunity to talk in detail about such an integral part of their daily lives. Most of those with previous contact with the mental health system had previously encountered similar clinical assessments, and seemed to enjoy the opportunity to demonstrate their experience, even if they might regard some of the questions as personally irrelevant.

More significant changes to our interview protocol were made early in the process, adding numerous open-ended questions about participants' goals in various life domains. This was done to balance the structured response format of the other measures, and to provide contextual information to the quantitative data. A more participant-centred approach might place more emphasis on qualitative methodology, which can be conceptually easier and more "user-friendly" for participants, but which requires considerable resources and specific expertise for analysis. In this case, our mixed-methods approach was more suited to the resources we had available.

We did adapt our questions on the basis of feedback we received from clients at the pilot-testing phase, particularly concerning the Satisfaction With Life Scale (Diener, Emmons, Larsen, & Griffiths, 1985). Though brief, this scale asks the participant to reflect on his or her life in a summative fashion, and to compare it with his or her personal ideal. We found that for those who had encountered great difficulties in their lives, and had had to postpone or give up on hopes and dreams, this self-reflection had the potential to be somewhat demoralizing. We realized we needed to find a way for interviewers to support participants through that experience, and so added the open-ended question, "How do you cope with the rough times?" Participants seemed to appreciate the implicit acknowledgement that they were, in fact, coping, and shared the rich variety of methods — both positive and negative — they had developed to deal with their difficulties. 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.

Procedures

It is now accepted that research with hard-to-follow populations must engage people on their own "turf" (e.g., McKenzie et al., 1999; Ribisl et al., 1996), whether that be at emergency shelters, soup kitchens, drop-ins, or day programs, sometimes even on the streets or under bridges. In the recruitment phase of our project, research staff went out with an outreach worker to all these settings to talk with clients about the research project and solicit 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. Researchers needed to be flexible and open-minded about when, where, and how to engage with prospective participants, as well as persistent and sensitive. 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 be in a position to give informed consent.

We also found the recruitment process to be a delicate balance of providing clients with the information they needed to give informed consent, while at the same time gauging their readiness to hear that information to avoid a premature refusal. This was important; refusal at this stage meant that individuals would not be eligible for CMHA's ICM service for two years, although they could be referred to another similar service in the community. 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 equally as well-informed a decision as consent. We soon realized this process required a sophisticated skill set, and had to delegate recruitment responsibilities to the two researchers who were most successful at engaging with clients, and whose schedules were flexible enough to meet them when they were ready.

Similarly, interviewing such a marginalized and disabled group of people requires a very specialized set of skills. It would not be an overstatement to say that the quality of our interviewers has been the key factor in our success at retaining participants in our study. All our interviewers were students in a doctoral program in clinical psychology, but this was not the most important criterion. We found the most successful interviewers were those who were interested in and comfortable with meeting people from very different circumstances from their own, and who had the sensitivity to ensure that

people felt respected and truly heard. Assessment skills were crucial; it was the interviewer's job to decide if a participant was too symptomatic to participate in the interview that day, or if a participant was becoming too fatigued and needed a break, or to continue the interview the next day. Throughout the interview, the interviewer had to be alert as to what impact the questions were having on the participant, so that interpretations were consistent, assessments were made thoroughly, and supports could be put in place after the interview, if necessary.

Given that many of the participants in our study had had traumatic experiences with males, female interviewers were absolutely necessary in many cases. For the most part, however, we found it advantageous to match interviewers to participants on the basis of personality and the skills of the interviewer, and less by demographic characteristics. For several people coping with severe depression, for example, we chose interviewers who were soft-spoken and who knew how to adapt their energy level and presentation so as not to overwhelm participants.

In our study, interviews were generally conducted in community settings such as offices in drop-in centres, shelters, and community health centres, or in a private location at the university, local library, or even in certain restaurants. We tried to provide participants with a choice of venues, ones that were familiar and in which they felt at ease, and to balance the need for privacy with that of safety for the interviewers. As such, interviews were seldom conducted in participants' homes, but if they were, it was generally with two interviewers present. Unlike many studies that used the same people to track and interview participants (e.g., Bootsmiller et al., 1998; Cohen et al., 1993; Gwadz & Rotherman-Borus, 1992), we found it was much more effective and efficient to centralize responsibility for planning followup interviews with the research coordinator. Since this person was located at the agency, she could work closely with program staff to get up-to-date information on participants' circumstances and also benefit from staff's own efforts to locate clients.

In order to help interviewers know how best to accommodate participants' needs during data collection, we provided extensive and ongoing training as well as participant-specific updates to interviewers. Indeed, interviewer training and support is becoming recognized as a critical element of evaluation research with hard-to-follow populations (see particularly Bootsmiller et al., 1998; Cohen et al.,

1993; Gwadz & Rotherman-Borus, 1992; Ribisl et al., 1996). As doctoral students in clinical psychology, all our interviewers had the clinical knowledge and skills required to recognize and accommodate most mental health issues that might be experienced by participants during the course of an interview. What most lacked, at first, was an understanding of what it is like to be homeless, such as the daily challenge of getting enough sleep and having to travel all over town for meals, appointments, and shelter. Our training curriculum explored these issues and their behavioural implications in detail, and gave practical advice on how to create a calm, relaxing, and successful interview experience for participants.

We also provided specific training and a protocol for suicide risk assessment and intervention. We were surprised by the frequency with which participants disclosed (unprompted) thoughts and experiences regarding suicide. As a result, we adapted our "scripts" at the informed consent and interview stages to qualify our assurance of confidentiality, so that participants understood the interviewers' obligation to inform the research coordinator or agency staff if s/he felt there was even a moderate risk for the participant (the coordinator, in turn, liaised with staff at the appropriate agency for intervention when necessary).

On a more general level, we found we had to allocate more of the research coordinator's time than planned for debriefing and support for the interviewers. This was particularly important after a difficult interview; interviewers had to deal with quite a range of challenging content and behaviours, such as from the participant who only wanted to discuss his instrumental role in the coming apocalypse. Even if the interview had gone reasonably well, however, interviewers sometimes felt overwhelmed by the complexity and severity of people's illnesses, and the lack of obvious solutions for their difficulties. It was important for us to recognize that the interviewers worked for the most part in isolation, and sometimes experienced role strain and a sense of marginalization (e.g., Cohen et al., 1993) that required sharing their feelings with someone who was familiar with the participant.

Finally, we tried to accommodate participants' needs with incentives for participation. Interviewers paid participants an honorarium of $20 for each completed interview, a process approved by the Research Ethics Board at the university. On rare occasions when a participant objected to the honorarium, we tried to find another acceptable means to acknowledge participation, such as the time we

bought cat food for a man who tended a herd of wild cats. Interviewers often bought juice or coffee for participants, and from time to time, lunch or breakfast, if the person were in particularly dire straits. We sometimes purposely arranged for the interview to be held near the end of the month, when the honorarium would help bridge the gap until the next social assistance cheque arrived. Conversely, we avoided scheduling interviews at cheque time for participants whom we knew 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 coercive, and this will vary according to the circumstances of the population involved. In our study, participants were all living in extreme poverty. We could not ask them to complete an interview if they were hungry, and it seemed unreasonable not to acknowledge their time, trouble, and expertise in a way they found meaningful. Moreover, honoraria had become the norm locally for community-based research with this population, and it is unlikely we would have been able to recruit and retain as many participants without them.

CONCLUSION

We have certainly learned as much from our mistakes on this project as from our successes, and in the process, we have also made some noteworthy discoveries. At a basic level, we have learned that successful research with hard-to-follow participants is a matter of utilizing not only strategies for tracking and follow-up, but retention strategies as well. To maximize participant retention, one must make participants' ongoing participation as effortless and rewarding as possible, whether in terms of meeting their material needs (e.g., for compensation or convenience) or responding to other motivations, such as for meaningful social contact or a sense of having contributed to a worthwhile endeavour. As in the literature, we have found three areas to be critical: (a) the characteristics of the researchers who contact and/or interview participants, (b) the relationships established between interviewers and participants, and (c) participants' motivation to follow-up.

In their focus on inter- and intra-personal characteristics and processes, retention strategies are fundamentally focused on the individual and his or her unique needs, rather than those of the study population as a whole. Adopting a participant-centred approach, we

have discovered, implies a much greater commitment than usual on the part of researchers; it entails a fundamental re-orientation of one's research design and methods toward understanding and meeting these individual needs. One must consider, for example, if and how participants with significant exceptional circumstances can be included in one's research design, and be prepared to over-sample and extend recruitment timelines in recognition that attrition will likely be high, regardless of one's best efforts. Customization of tracking and follow-up strategies is key, as is extensive pilot testing of interview instruments and flexible procedures for their administration.

No matter how prepared one is in advance, however, adopting a participant-centred approach involves moving past one's assumptions and biases to better know and adapt to the individuals involved. In our case, even those of us on the research team with extensive experience with this population had to rethink our assumptions and relearn as we adjusted our procedures to meet the needs of these *particular* participants. Initially, for instance, everyone involved in the project was 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 found, however, that our interview protocol took less time to complete than first anticipated (on average, an hour and a half), and while fatigue was certainly an issue for many participants, for the most part this was dealt with easily by paying attention to pacing, suggesting breaks, or doing the interview in two parts. We were particularly surprised by how well people with very challenging symptoms managed the interview, although it was clear that for some, this took significant effort. The surprise was that they were willing to make the effort, not once, but several times, and most said they enjoyed the process.

As this example illustrates, when conducting research with hard-to-follow populations, it is vital to be as knowledgeable as possible about their circumstances and needs, but this in itself is not sufficient; it is also critical to inform oneself about the unique needs of specific participants, and allow enough flexibility in one's research protocol to adjust and adapt to this knowledge throughout the process. We think the active involvement of key informants and participants themselves is critical to enhancing this knowledge and the process of adaptation, and in our experience, advisory groups, inclusive research teams, and extensive pilot testing of instruments are very effective mechanisms. Participatory-action research and

qualitative methodologies (or as many elements of these as possible) would be a significant aid in keeping participants' needs foremost throughout the research process.

We also think this reveals one of the most valuable aspects of working with marginalized and hard-to-follow 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 benefit. The challenge, then, is to take that experience and make it of equal value to the participants in one's research; to provide substantial and tangible benefit for them, not only for the duration of the study, but afterward, in the form of real contributions to program improvement and social policy.

ACKNOWLEDGEMENTS

REFERENCES

Aubry, T., Klodawsky, F., Hay, E., Nemiroff, R., & Hyman, S. (2004). *Developing a methodology for tracking persons who are homeless over time*. Ottawa: Canada Mortgage and Housing Corporation.

Barker, S., Barron, N., McFarland, B.H., & Bigelow, D.A. (1994). A community ability scale for chronically mentally ill consumers: Part I, reliability and validity. *Community Mental Health Journal, 30*, 363–379.

Belcher, J.R., & Toomey, B.G. (1988). Relationship between the deinstitutionalization model, psychiatric disability, and homelessness. *Health & Social Work, 13*(2), 145–153.

Bootsmiller, B.J., Ribisl, K.M., Mowbray, C.T., Davidson II, W.S., Walton, M.A., & Herman, S.E. (1998). Methods of ensuring high follow-up rates: Lessons from a longitudinal study of dual diagnosed participants. *Substance Use & Misuse, 33*(13), 2665–2685.

Cheung, A.M., & Hwang, S.W. (2004). Risk of death among homeless women: A cohort study and review of the literature. *Canadian Medical Association Journal, 170*(8), 1243–1247.

Cohen, E.H., Mowbray, C.T., Bybee, D., Yeich, S., Ribisl, K., & Freddolino, P.P. (1993). Tracking and follow-up methods for research on homelessness. *Evaluation Review, 17*(3), 331–352.

Cottler, L.B., Compton, W.M., Ben-Abdallah, A., Horne, M., & Claverie, D. (1996). Achieving a 96.6 percent follow-up rate in a longitudinal study of drug abusers. *Drug & Alcohol Dependence, 41*(3), 209–217.

Cousins, J.B., & Whitmore, E. (1998). Framing participatory evaluation. In E. Whitmore (Ed.), *Participatory evaluation approaches*. New Directions in Evaluation, No. 80 (pp. 5–23). San Francisco: Jossey Bass.

Dennis, D.L., Buckner, J.C., Lipton, F.R., & Levine, J.S. (1991). A decade of research and services for homeless mentally ill persons: Where do we stand? *American Psychologist, 46*, 1129–38.

Desmond, D.P., Maddox, J.F., Johnson, T.H., & Confer, B.A. (1995). Obtaining follow-up interviews for long-term evaluation. *Journal of Substance Abuse Treatment, 12,* 95–102.

Diener, E., Emmons, R.A., Larsen, R.J., & Griffiths, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment, 49*(1), 71–75.

Dilonardo, J.D., Kendrick, K.A., & Vivaldi, K.B. (1993). Chronic or long-term psychiatric patients: Potential subjects for longitudinal research. *Issues in Mental Health Nursing, 14,* 109–118.

Gondolf, E.W. (2000). Human subject issues in batterer program evaluation. *Journal of Aggression, Maltreatment & Trauma, 4*(1), 273–297.

Gunderson, T.L., & McGovern, R. (1989). *How to locate anyone anywhere without leaving home*. New York: Dutton.

Gwadz, M., & Rotheram-Borus, M.J. (1992). Tracking high-risk adolescents longitudinally. *AIDS Education & Prevention,* (Suppl Fall), 69–82.

Hartsough, C.S., Babinski, L.M., & Lambert, N.M. (1996). Tracking procedures and attrition containment in a long-term follow-up of a community-based ADHD sample. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 37*(6), 705–713.

Hiroeh, U., Appleby, L., Mortensen, P.B., & Dunn, G. (2001). Death by homicide, suicide, and other unnatural causes in people with mental illness: A population-based study. *Lancet, 358,* 2110–2112.

Hwang, S.W. (2000). Mortality among men using homeless shelters in Toronto, Ontario. *Journal of the American Medical Association, 283,* 2152–2157.

Katz, K.S., El-Mohandes, A., Johnson, D.M., Jarrett, M., Rose, A., & Cober, M. (2001). Retention of low income mothers in a parenting intervention study. *Journal of Community Health: The Publication for Health Promotion & Disease Prevention, 26*(3), 203–218.

McKenzie, M., Peterson Tulsky, J., Long, H.L., Chesney, M., & Moss, A. (1999). Tracking and follow-up of marginalized populations: A review. *Journal of Health Care for the Poor and Underserved, 10*(4), 409–429.

Menard, S. (1991). *Longitudinal research.* Newbury Park, CA: Sage.

Morrissey, J.P., & Dennis, D.L. (1990). *Homelessness and mental illness: Toward the next generation of research studies.* Rockville, MD: National Institute of Mental Health.

Overall, J.E., & Gorham, D.R. (1962). The Brief Psychiatric Rating Scale. *Psychology Reports, 10*, 799–812.

Passetti, L.L., Godley, S.H., Scott, C.K., & Siekmann, M. (2000). A low-cost follow-up resource: Using the World Wide Web to maximize client location efforts. *American Journal of Evaluation, 21*(2), 195–203.

Rajotte, E., Fuchs, C., & Zatzick, D. (2003). Engaging and following trauma survivors in real world clinical investigations. *Journal of Nervous & Mental Disease, 191*(4), 265–268.

Ribisl, K.M., Walton, M.A., Mowbray, C.T., Luke, D.A., Davidson II, W.S., & Bootsmiller, B.J. (1996). Minimizing participant attrition in panel studies through the use of effective retention and tracking strategies: Review and recommendations. *Evaluation & Program Planning, 19*(1), 1–25.

Rumptz, M.H., Sullivan, C.M., Davidson II, W.S., & Basta, J. (1991). An ecological approach to tracking battered women over time. *Violence and Victims, 6*(3), 237–244.

Shadish, W.R., Cook, T.D., & Campbell, D.T. (2002). *Experimental and quasi-experimental designs for generalized causal inference*. Boston: Houghton Mifflin.

Skinner, H.A. (1982). The Drug Abuse Screening Test. *Addictive Behaviors, 7*(4), 363–371.

Susser, E., Goldfinger, S.M., & White, A. (1990). Some clinical approaches to the homeless mentally ill. *Community Mental Health Journal, 26*(5), 463–480.

Toro, P.A., Passero Rabideau, J.M., Bellavia, C.W., Daeschler, C.V., Wall, D.D., Thomas, D.M., & Smith, S.J. (1997). Evaluating an intervention for homeless persons: Results of a field experiment. *Journal of Consulting & Clinical Psychology, 65*(3), 476–484.

Woody, G.E., Metzger, D., & Mulvaney, F. (1994). Preparation for AIDS vaccine trials: Recruitment and retention of in and out-of-treatment injection drug users. *AIDS Research Human Retroviruses, 10*(Supp 2), S197–9.

Heather Smith Fowler, B.A., M.A., is the research manager of the Women's Health Research Unit at the Institute of Population Health, University of Ottawa.

Tim Aubry, Ph.D., is an associate professor in the School of Psychology and director of the Centre for Research on Community Services at the University of Ottawa.

Marnie Smith, B.Sc.N., M.S.W., is a program manager at the Canadian Mental Health Association, Ottawa Branch.