

A BENEFIT FOR EVERYONE: FAMILY-RESEARCHER COLLABORATION IN THE MENTAL HEALTH FIELD

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Abstract: This article outlines the benefits of family member involvement at all stages of mental health research. As an integral aspect of a longitudinal study of family self-help/mutual aid organizations, family members participated as advisors, researchers, and knowledge translators. Their participation served to improve the research design, inform the research questions, enhance the quality of the data, and assist in knowledge translation. Reciprocal benefits to the family members include increased research capacity, self-esteem and empowerment, financial remuneration, and a sense of ownership in the research. Innovative methodologies that consider families as full participants in all aspects of ongoing program evaluation research are recommended.

Résumé: Cet article décrit les avantages de la participation des membres de la famille à toutes les étapes de la recherche en santé mentale. Dans le cadre d'une étude longitudinale portant sur les groupes d'entraide, les membres de la famille ont participé en tant que conseillers, chercheurs, et traducteurs de connaissances. Leur participation a permis d'améliorer la conceptualisation de la recherche, de préciser les questions de recherche, de hausser la qualité des données, et à traduire les connaissances. Les avantages pour les membres de la famille sont, entre autres,

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des capacités de recherche accrues, l'estime de soi et l'habilitation, la rémunération, et un sentiment d'appropriation de la recherche. Des méthodologies innovatrices qui considèrent les familles comme étant des participantes à part entière à tous les aspects de la recherche en évaluation de programme sont recommandées.

There is a paucity of collaborative approaches to designing, conducting, interpreting, and disseminating research on consumer outcomes and satisfaction in the mental health literature (Byas et al., 2003). With few exceptions, it has been an uncommon phenomenon for consumers to be actively involved in mental health research and evaluation beyond the role of research subjects (Lord, Ochocka, Czarny, & MacGillivray, 1998; Morrell-Bellai & Boydell, 1994; Reeve, Cornell, D'Costa, Janzen, & Ochocka, 2002). There is, however, a growing awareness that the relationships among mental health consumers, caregivers, researchers, and decision-makers need to be both collaborative and consumer-driven (Henry, Nicholson, Phillips, Sytier, & Clayfield, 2002; Jivanjee, Schutte, Robinson, & Koroloff, 2004). Current mental health reform highlights the need to give more credibility and support to consumer and family experience and knowledge (Boydell, Gladstone, & Crawford, 2002). In the area of service delivery, there has been a proliferation of literature on consumer involvement, often focused on the employment of consumers as case manager aides in the formal mental health system (Macdonald, Herrman, Hinds, Crowe, & McDonald, 2002; Manning & Suire, 1996). These efforts recognize that employees who are consumers can bring unique skills and perspectives to the mental health service system. Concomitant with this, literature on consumers as service employees has been focused on the involvement of consumers as researchers in projects dealing with adult mental health (Morrell-Bellai & Boydell, 1994; Ochocka, Janzen, & Nelson, 2002; Vandergang, 1996; Woodside, Cikaló, & Pawlick, 1995). We argue that family members whose relatives have a mental illness are also consumers of mental health services and need to have a voice in research as well. Furthermore, the involvement of family members at all stages of research serves to benefit both parties.

FAMILY PARTICIPATION IN MENTAL HEALTH RESEARCH

One application of participatory research is in the area of evaluating services and supports for people with mental illness and their families. Participatory approaches augment the relevance, useful-

ness, and application of research data and have the potential to bridge cultural disparities (Cousins & Earl, 1995). Such approaches are important, as traditional methods of evaluation often fail to serve the interests of the individuals being studied (Vander Stoep, Williams, Jones, Green, & Trupin, 1999). To address this, research agendas, priorities, questions, methods, and outcomes are increasingly being conceptualized under the rubric of a new paradigm that acknowledges the value of the life experiences of families whose relatives have serious mental illness (Osher, Van Kammen, & Zro, 2001). Programs are beginning to incorporate family strengths and family-based perspectives into evaluation research (Werrbach & Perry, 1996). In fact, participatory research and family collaboration have become a maxim for policy makers, clinicians, researchers, and mental health advocates (Swan & Morgan, 1991).

As family members become less intimidated working within the traditional realm of the researcher, they recognize more fully the potential power of research to help families. Concomitant with this is the need to conduct well-designed studies to actualize this power. Researchers also recognize the potential power of family members vis-à-vis their role in strengthening research efforts and the associated need for strong community partnerships (Vander Stoep et al., 1999). Turnbull, Friesen, and Ramirez (1998) outlined six levels of family participation in research, moving from least to most involvement: (a) families as research subjects, (b) families as advisory board members, (c) families as occasional reviewers and consultants, (d) researchers as leaders and families as ongoing advisors, (e) researchers and families as co-researchers, and (f) families as research leaders and researchers as ongoing advisors.

This article reports on the experience and implications of a collaborative research project involving family members and researchers. Participation corresponded to levels (d) and (e) described above, that is, researchers as leaders and families as ongoing advisors, and researchers and families as co-researchers. The research goal of the project was to examine the impact of family self-help groups on family members who have an adult relative with a serious mental illness. The process goal was to involve family members as partners in the study and to provide them with the basics of research methodology so that they could assume collaborative roles. The project described herein focuses on family members as ongoing advisors, co-researchers, and knowledge translators. The conceptual framework we used was based on the model of collaborative research posited by Reason

and Heron (1995) and the practical implementation of this approach employed by Portland State University's Research and Training Center on Family Support and Children's Mental Health. The mandate of Portland's family collaborative and family-centred model is to encourage and support family partnership in all aspects of service delivery and evaluation, including development, interpretation, and dissemination. Family members are trained and supported regarding their involvement as researchers and evaluators. The Portland model describes the potential roles of family members including advocate, research associate, consultant, and advisor. Such collaborative research challenges the notion that researchers are experts on what outcomes are to be studied and what the outcomes imply about participants. Rather, participants are viewed as co-researchers, who shape what is most critical to research and how it occurs.

OBJECTIVES OF INVOLVING FAMILY MEMBERS

Based on some of our earlier work examining the experiences of people with psychiatric disabilities employed as researchers (Morrell-Bellai & Boydell, 1994), we found that research quality was enhanced by the insider perspective brought by consumer-researchers. Our objectives in this study were to bring community stakeholders (family members) and researchers together in order to determine the research questions, the approaches used to obtain information, and, most importantly, the meaning of the results and how they should be used to benefit the community. We also wanted to build community involvement in partnerships that are sustained through research and to foster and leave behind skills and capacities on the part of both traditional research institutions and communities. In addition, there was a desire to involve people normally excluded from research and information gathering.

OVERVIEW OF THE STUDY

"A Longitudinal Analysis of Family Initiatives in Community Mental Health in Ontario" (Family Study) was a five-year study conducted as part of the Community Mental Health Evaluation Initiative (CMHEI) in Ontario, Canada. Funded by the Ministry of Health and Long-Term Care, the CMHEI consisted of eight projects in four Ontario centres. The CMHEI was designed to determine the effectiveness of community-based mental health services and supports. Conceived by four partners, the Canadian Mental Health

Association–Ontario Division, the Centre for Addiction and Mental Health, the Ministry of Health and Long-Term Care, and the Ontario Mental Health Foundation, the CMHEI is the first broad-scale, integrated assessment of the effectiveness of such community-based mental health services and supports as assertive community treatment, intensive case management, crisis response services, and consumer/survivor and family self-help/mutual aid initiatives.

Self-help/mutual aid initiatives differ fundamentally from professional services (Trainor, Shepherd, Boydell, Leff, & Crawford, 1997). Reliance is primarily on the collective, experiential knowledge possessed by members, and the process of exchanging help is usually free of professional assumptions (Jacobs & Goodman, 1989). These organizations offer key processes (encouragement, self-disclosure, and opportunities to receive and provide support) as well as key activities (social events, advocacy, education, and support) that can empower and strengthen families (Weissbourd & Kagan, 1989). Despite variations among such groups, the sharing of experience among people with similar issues is the fundamental concept that distinguishes this helping approach from other helping exchanges (Mannion, Meisel, Solomon, & Draine, 1996).

The goal of the Family Study was to evaluate the impact of family self-help/mutual aid organizations at both the individual and systems levels using quantitative and qualitative methods. At the individual level, the quantitative component consisted of interviews with 279 members at baseline, 9, and 18 months regarding their experience of participation, empowerment, social support, coping, and burden. Family experiences of hope and stigma were also assessed. A subset of 19 individuals was interviewed qualitatively about their pathways to self-help and the impact of their involvement in the organization. At the systems level, we documented the ways in which family organizations educate the public and professionals about mental illness, get involved in community planning, and advocate for organizational, community, and social change. The study was approved by both university and hospital research ethics boards. The results of these components of the study are reported elsewhere (Boydell, Trainor, & Jadaa, 2003). This article reports on the four ways that family members were involved in this research project. Family members were involved as collaborators to the funding proposal, as employed research assistants, as expert advisors, and as knowledge translators.

METHODOLOGY

The data sources used to document the involvement of family members in each of the four areas are documented in Table 1. These data sources comprise the textual data that this report is based on. Analysis of the data involved thematic content analysis, a dynamic form of analysis of verbal data oriented toward summarizing the informational content and describing the patterns and regularities in the data. The principal investigator reviewed the data transcripts first to gain an overall sense of the content, and then again in order to identify important themes and key concepts. Remaining investigative team members participated in a meeting to discuss and consolidate the main messages related to family member involvement.

Table 1
Data Sources

Area of Family Involvement	Source of Data
As collaborators to funding proposal	Planning committee minutes, investigative team notes
As employed research assistants	Family study meeting minutes, investigator study meeting field notes, exit interviews
As expert advisors	Focus group transcripts and field notes
As knowledge translators	Documentation of presentations of study results at conferences and SHMA organizations

FAMILY MEMBERS AS COLLABORATORS TO THE FUNDING PROPOSAL

We concur with Parker's (1999) suggestion that it is critical to define "research goals with those we are researching" (p. 97). Representatives of family organizations were involved in the earliest stages of the project, helping us to define research objectives and having input into how the project should be organized. More specifically, family members and staff worked with the research team to develop the questions that were the focus of the study. This provided a rich opportunity for exchanging knowledge about the subject matter. The goal of having families and staff of the self-help organization assist in identifying the focus of the study was to increase the relevance of the research, enhance empowerment of researchers, families, and other stakeholders, and ultimately, increase utilization of the research by families.

Family member involvement influenced proposal development in several significant ways. When the call for proposals was initially released, the investigative team hosted a meeting to discuss the potential of moving forward with the development of a grant application. This meeting included researchers from different Ontario locations, consumers of mental health services, family members, and service providers. The original Request for Applications (RFA) included a call for research focusing on self-help/mutual aid organizations. It was assumed that any grant submitted in this area would focus on both consumer-run and family-run initiatives. It was at this initial stage that our consumer and family community partners identified the need to submit two unique proposals, thus separating consumer-run and family-run self-help initiatives. The research scientists in the room indicated that they had no particular preference in terms of which proposal they would take the lead role on. Consequently, they removed themselves from the room, and the remaining meeting participants (non-researchers) decided which research team members would lead each of the two proposals to be developed. This example reflects the important decisions that were made very early on in the project as a result of family members and consumers being part of the application process. It is important to note that many of the meeting attendees were known to each other through previous collaborative partnerships between the researchers and the front-line service providers, families, and consumers. These previous positive working relationships may have enhanced the trust among key players at this initial meeting.

Another way that family members assisted in project development demonstrates the need of families to provide input based on their lived experience. One of the key concepts that we were measuring (based on the empirical and theoretical literature) in terms of the impact of the self-help/mutual aid groups was burden. The term “burden” was clearly problematic for family members. They felt that it was an extremely negative term and did not think of their ill relative as a burden to them. After a great deal of discussion, it was felt that academically, it was awkward to use another, more preferred term — such as family strain — as all of the literature in the area used the term burden. In the end, the entire collaborative team decided to use the term, but with a disclaimer that expressed the views of family members written directly into the proposal.

Family members also stressed that stigma was a pervasive element of their experience — this stigma was directed toward both them-

selves and their ill relatives. They felt that it was critical to measure the extent to which family members of self-help/mutual aid organizations experienced stigma. They also indicated that having hope and/or being hopeful was very important to measure in our examination of the impact of their membership in self-help/mutual aid organizations. They seemed well aware that there was little discussion of this important concept, either informally or in the published literature. The examination of these concepts was so crucial to our family advisors that they were willing to have a longer interview schedule to accommodate measurement. Attending to the views of family members and making changes to the study protocol as a result helped to minimize any extant power differentials between family and researcher team members.

FAMILY MEMBERS AS EMPLOYED RESEARCH ASSISTANTS

Eleven research assistants (RAs) were hired to recruit and conduct interviews with family members of the three self-help/mutual aid organizations involved in the research. They were recruited in a variety of ways, including recommendations from staff of the family self-help/mutual aid organizations, flyers posted in the organization, and advertisements in family member newsletters that were distributed to all members. Eight of these RAs were family members of the organizations. The entire RA group participated in a two-day training session in order to acquire the skills necessary for recruitment and interviewing. The training session involved a detailed overview of the study, an overview and discussion of recruitment strategies, a review of the interview schedule and process, and a series of mock interviews. A discussion was also held on the issue of confidentiality. It was emphasized that confidentiality was critical, that anything research assistants heard could not be shared with anyone outside of the research team, and that no names could be attached to the information. The RAs understood that participants were free to refuse to participate, to withdraw at any time, or to refuse to answer any questions posed to them. In addition to this formal training, all RAs were provided with regular and ongoing mentoring, provided by the project coordinator for the study.

Monthly meetings of the entire investigative team were held. These meetings informed our research in significant ways. They provided an opportunity for the research assistants to share their experiences of being in the field with each other. They identified successful recruitment strategies and areas of the interview schedule that proved

to be challenging. One example of a challenge encountered in the field was the identification of a group of family participants who expressed frustration with the quantitative interview schedule as they felt they were not given an opportunity to tell their story. They questioned whether the research would be able to identify the true impact of their involvement through the use of these questionnaires. Research assistants were able to inform them that there was also a qualitative component to the study, wherein families would have the opportunity to speak in a relatively unstructured manner and identify the details of their involvement as members of a self-help/mutual aid organization. These monthly meetings were also tremendously helpful to the investigative team and other non-family research assistants, as we were able to discern the lived experience of our research assistants who were family members, dealing with their own ill relative on a day-to-day basis.

The impact of hiring family members of self-help organizations as research assistants was experienced at a number of different levels. In terms of the investigative research team, we felt that their contribution to the study was immeasurable. We were constantly surprised at the assumptions that are often made in the research process — our family member research assistants questioned these assumptions and led us to ask important questions that we otherwise may have missed. In addition, we were able to obtain an insider perspective on the realities of caring for a relative with a serious mental illness. This highlighted the importance of experiential knowledge. Family members are truly experts regarding their own experiences, and this, in turn, can shape research questions and ways in which the research information is collected.

Our family research assistants also expressed that they had benefited from this experience. In an effort to more fully understand this, we specifically asked family research assistants, in an “exit” interview, to talk about what it had been like for them to be a part of this study. Minutes from our monthly meetings and personal recollections have also served to inform us of the advantages experienced by our family research assistants.

During team meetings and exit interviews, family research assistants revealed that their self-esteem was enhanced as a result of their participation in this research. As one family member stated, “This position has helped me to be more self-sufficient and has boosted my ego. I love doing the interviews and talking to other people.”

Two of the research assistants were senior citizens who commented on how proud they were to be employed in a meaningful way at their age.

Training and employment as a family member research assistant had more tangible benefits as well. Four of the eight family member research assistants found subsequent full-time employment in the mental health field, greatly enhancing capacity in this area. The financial remuneration also helped to supplement the income of our researchers, which for some was much needed. It is also important to note that all of our family study RAs were compensated at rates that were established for research assistant staff at the institution responsible for distributing funds.

Our family member research assistants spoke of their pleasure in meeting the other people involved in the study. For some, the position allowed them to “get out of the house” and participate in an active way in the world. A few of the researchers formed friendships with those they interviewed that lasted beyond the length of the study. In this way, the social support networks of both family members and researchers were increased. Some research assistants reported a change in perspective in relation to themselves, their families, and the nature of their contact with the family organization as a result of their interactions interviewing family members. As one research assistant voiced, “I got quite a few tips on quite a few things. I also discovered that my son isn’t all that ill, which is very reassuring, because I heard so many other horrible stories.” A number of the research assistants became more actively involved in their family organizations as a result of their involvement in this study. “As a result, I became more actively involved in the [family organization]...I’m on the executive now...I wanted to give something back.”

FAMILY MEMBERS AS EXPERT ADVISORS

A focus group was held with four of the family member research assistants once they were well on their way in terms of interviewing other family members. The purpose of this focus group was to develop the guideline interview schedule for the qualitative component of the study. Based on thematic analysis of the focus group discussion, we developed a semi-structured interview, consisting of open-ended guideline questions regarding the pathways into self-help/mutual aid and the impact of membership in such a group. Our original intent was to embellish the questions regarding the impact

of the self-help group on the day-to-day lives of self-help members. Our family member researchers informed us that, based on their interviews with family members for the quantitative component of the study, there was a desire from families to tell the story of how they came to be involved in a self-help/mutual aid group. Specifically, they wanted to outline some of the barriers and facilitators to participation that they had encountered. Consequently, the research team decided that it would be important to address the topic of pathways to self-help as well as impact.

We were also told that many of the family member participants were extremely frustrated by the measurement instruments that were implemented during the quantitative interview. Families felt limited by the questionnaire's structure and frustrated by trying to fit their experience into the Likert rating scales. Furthermore, they did not feel that they had the opportunity to talk fully about their involvement in the self-help group.

FAMILY MEMBERS AS KNOWLEDGE TRANSLATORS

The family organizations participating in this study are the three main groups of their type in Ontario. Because of the involvement of these organizations from the initial phase of the research, they now feel a sense of ownership and connection with the study. Their collective organizational strength and lobbying power will ensure two things: the dissemination of results to their own members and the communication of the results to key players in the mental health system including hospitals, community agencies, and the provincial government. It is important to add that families also motivate researchers to speak and write in a language that is comprehensible to the general public.

The role of family organizations is essential in the arena of research communication for a variety of reasons: their own members are unlikely to read research results in journals and as a result might miss the findings; many hospital and agency staff do not consider family issues to be important and may need to be lobbied aggressively; and governments make decisions about health matters that are influenced as much by political pressures as by research findings. In this case, family lobbyists will bring both to the table. Furthermore, we have already begun to see some evidence of translation of our research results. The investigative team has presented both process and outcomes of the research to family organizations, and these pres-

entations have had a ripple effect in terms of audience members sharing the findings with other family members in their organization. In addition, one of our family member research assistants was invited to be a discussant at a large scientific conference at a plenary session on the value of self-help. Privileging the views of family members in this way and recognizing their expertise was acknowledged by other family member conference participants.

DISCUSSION

There is much to be gained by using a collaborative research conceptual approach (Reason & Heron, 1995) to family involvement that acknowledges the potential participation in research at a number of diverse levels (Jivanjee, Schutte, & Robinson, 2003). The involvement of family members at all stages of our research served to benefit both parties. This project has developed a group of family members who are well skilled in research techniques and a group of research scientists who are sensitive to family issues. Family members who were trained as research assistants now have opportunities for further paid employment in the research field. It is also empowering for families to perceive other family members of relatives with mental illness as being a valued part of the research process. The collaborative research design is not restricted to the mental health arena and can be easily transported to other health contexts.

There was little conflict between families and the research team throughout the multiple phases of their involvement. This may have occurred because of the previous working relationships that existed between many of the players. At the outset, the research team stressed the importance of recognizing the expertise of everyone on the team and not privileging any form of knowledge. We clearly conveyed our belief that the strengths of all members of the research team are invaluable to the research. This message was reinforced throughout the project.

Research teams have found that family members involved in conducting the research share common experiences with research participants (Jivanjee et al., 2003), and this was most certainly the case in our study. These family researchers are more likely to gain the trust of research participants, and they are more likely to get accurate information from participants (Jivanjee et al.). Family member researchers assume a unique and important role for families, serving to authenticate families' experiences through the interview

process (Werrbach & Perry, 1996). Research becomes more relevant by having family members help identify the focus of the study, develop the research questions, conduct the interviews, and participate in knowledge transfer. Innovative methodologies that consider families as full participants in all aspects of ongoing program evaluation research must be considered if we are to maintain our commitment to enhancing family mastery, broadening the ownership base, shifting power and control, and expanding opportunities for family-professional collaboration.

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