THE EXPERIENCE OF MENTAL HEALTH CONSUMERS AS RESEARCHERS

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ABSTRACT

The purpose of this study was to examine the experiences of six mental health consumers who were involved in paid employment as researchers in the mental health field. Semi-structured interviews were conducted with these individuals in order to identify any benefits experienced as a result of their employment and to identify special needs that should be considered when employing consumers. Although consumers felt they had benefitted from their employment, several unmet needs were identified. The study findings support both the benefits experienced by mental health consumers who are employed as researchers and the necessity of providing meaningful opportunities for them to give feedback on their experience.

Recent government documents in Canada advocate the involvement of mental health consumers in the planning, delivery, and evaluation of mental health services and programs (Graham, 1988; Minister of National Health and Welfare, 1988). These government documents have resulted in increased consumer involvement. However, the special needs that should be considered when involving consumers have not been adequately addressed. This paper will explore the experiences of six mental health consumers who were employed as researchers in a provincial psychiatric teaching hospital. Based on their experiences, an attempt will be made to extrapolate special needs that should be taken into account when employing consumers as researchers in the mental health field. In addition, the personal benefits experienced by these six individuals as a result of their employment will be explored. Finally, the effect, if any, on the quality of the obtained data will be briefly considered.

CONSUMER INVOLVEMENT

Few published examples of consumer involvement in mental health planning, delivery and evaluation exist (Church & Reville, 1989; Lord, 1989; Ridgway, 1988).

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Church and Reville (1989) note that consumer involvement in Canada is in an "embryonic stage" characterized by trial and error and that communication among professionals working in this area is sporadic. Consumers may be paying a high price in terms of lost confidence and mental health breakdown as they wait for professionals to develop models of participation that are effective and non-exploitative (Church & Reville, 1989). It is vital that mental health professionals who are attempting to involve consumers document the process so that future mistakes, many of which may be painful and damaging, can be avoided.

The literature on consumer involvement as researchers in the mental health field is very sparse. However, it is reasonable to assume that the experiences of consumers who are involved in mental health service planning and delivery are similar to the experiences of those involved in mental health evaluation. Therefore, throughout this paper reference will be made to the broader body of literature on consumer involvement in service planning and delivery.

THE BENEFITS OF CONSUMER INVOLVEMENT

The benefits of involving consumers in service planning, delivery, and evaluation are numerous. Although most consumers lack professional training in mental health, they possess experiential knowledge of mental illness and the mental health system. This direct experience can assist other consumers in identifying services that are relevant, acceptable, and likely to be utilized (Kopolow, 1981; Pape, 1988; Ridgway, 1988; Wilson, Mahler, & Tanzman, 1990). When provided the opportunity, consumers often demonstrate tremendous commitment and may help sensitize professional staff to their needs (Wilson et al., 1990).

Campbell and Schraiber (1989) observe that involving consumers as researchers addresses the short-sightedness related to interpreter error. Professionals may draw inaccurate conclusions as they attempt to make sense of data in light of the existing professional literature or observation of their clients. Although each consumer's experience of mental illness is unique, there are commonalities which may facilitate more valid interpretations. Hall (1992), in his discussion of participatory research methods, makes a similar point when he asserts that involving participants in research as co-researchers provides a more accurate picture of complex reality (p. 14). It has also been suggested that interviewees feel more comfortable when interviewed by a peer (Finch, 1984) and may therefore provide better data (Srebnick, Robinson, & Tanzman, 1990).

In addition to the external benefits discussed above, consumers may experience many personal benefits as a result of their involvement, including financial reward, empowerment, the development of vocational skills, the provision of role models and associated optimism about recovery, increased dignity and self-esteem, and decreased stigma (Kopolow, 1981; Pape, 1988; Ridgway, 1988; Smith & Ford, 1986; Srebnick et al., 1990; Wilson et al., 1990).

NEEDS TO CONSIDER WHEN INVOLVING CONSUMERS

Unfortunately, consumer participation in and of itself does not guarantee the benefits described above. There are a number of potential needs that should be taken into account by any agency that is considering involving consumers. Perhaps

the most important need to consider is remuneration. Although some authors point to the financial benefits of employing consumers who can be paid at a lower rate (Kopolow, 1981), many caution against this practice and emphasize the importance of adequate pay and reimbursement of expenses (Reville, 1991; Valentine & Capponi, 1989). Mowbray, Chamberlain, Jennings, and Reed (1988) conclude that the high consumer-volunteer turnover that characterized their peer-support project could be attributed to high demands and the fact that consumers were not paid for their work.

Even when consumers are paid for their involvement, the experience can be very disempowering if they are not viewed as equals by their professional co-workers. Consumers should have legitimate decision-making power and an impact on the policies and practices of the agencies with which they work (Church & Reville, 1989; Minister of National Health and Welfare, 1988; Smith & Ford, 1986). When involving consumers in research, it is essential that they be involved in the entire research process from the design stages to the final write up (Everett & Steven, 1989). Many professionals believe consumers are incapable of identifying their own needs (Kopolow, 1979) and professionals are often unwilling to give up the power and control they have traditionally possessed (Boudreau, 1990). This loss of control may be experienced most sharply when consumers are involved throughout the research process. Lord (1989) notes that the combination of traditional professional power and control and consumer vulnerability can stand in the way of true partnership. Despite their considerable knowledge, consumers may hesitate to express their ideas and may easily accept the professional's view.

Like most of us, consumers also benefit from regular feedback on their work. Church and Capponi (1991) note that institutionalization renders many consumers dependent, submissive to authority, and unaware of their rights and abilities. For consumers who are new to participation, it may take considerable time to regain their self-confidence. Professionals can facilitate this process by acknowledging the contributions consumers make and by providing positive feedback for work well done (Ridgway, 1988; Smith & Ford, 1986; Wilson et al., 1990).

In addition to nurturing self-confidence, agencies which employ consumers should also provide a safe environment in which they can ask for both practical and emotional support and discuss any discrimination they may have experienced in the workplace (Sherman & Porter, 1991; White, 1989; Wilson et al., 1990). The stress that most people experience with role change may result in increased disability for consumers (Sherman & Porter, 1991; Wilson et al., 1990). The need for emotional support should not be viewed as evidence of incompetence. White (1989), in a personal account of her experience as a consumer on a planning committee, notes that professionals should be available for support, not treatment, and should allow the consumer to remain in control.

Wilson and her colleagues (1990) note that all employees should be provided "reasonable accommodations" for interruptions of their work schedule, but that consumers may require additional accommodations such as: the need for short flexible hours, paid mental health leave, or allowances for slower work or simplified tasks when they are having difficulties. Finally, most consumers have not had the benefit of specialized training and should be provided sufficient training and al-

lowed time to develop the skills necessary for effective participation (Wilson et al., 1990).

METHODOLOGY

The purpose of this study was to examine the experiences of six mental health consumers who were employed as researchers in the Community Support and Research Unit (C.S.R.U.) at Queen Street Mental Health Centre in Toronto. The C.S.R.U. provides housing and income-maintenance support services to clients and former clients of the hospital. Four separate research projects were examined, involving six consumer researchers. These research projects will be briefly described prior to describing the methodology utilized in the present study.

These efforts to employ consumers as researchers were undertaken in response to the recent literature on consumer participation which is reviewed in this paper: specifically, the desire to acknowledge the skills consumers bring to the research; the assumption that data quality would be improved; and the desire to provide positive benefits to consumers including financial rewards, the development of vocational skills, increased self-esteem, possible empowerment, and decreased stigma.

In order to discover differences in the employment experiences of the six consumer-researchers which might be directly attributable to the circumstances of their employment, the four "employment circumstances" will now be described. The names (or pseudonyms) of these six individuals will also be included in this section to facilitate clarity in the results section.

1. Consumer-Researcher Employment in Hospital Strategic Planning

The first research project which involved a consumer as a paid researcher explored inpatient and outpatient perceptions of the role of the hospital as part of its strategic planning exercise. "Nola" was hired and was involved with hospital administration and C.S.R.U. staff to design the questionnaire. Her input was invited throughout the process, and was incorporated in the final measurement instrument used. She was responsible for conducting semi-structured interviews, both in the hospital and in the community, and she assisted with the data analysis and writing of the final report for hospital administration. She was given her own office to work in and was involved in the entire research process from design stage to completion.

2. Consumer-Researcher Employment in a Quantitative Evaluation of a Co-op Housing Project

Three consumer-researchers, "Allan," "Jenny," and "John," were serially hired to evaluate two co-operative housing projects supported by C.S.R.U. Jenny was the only consumer employee of the six with previous research experience. Each was hired to administer quantitative measurement tools to tenants, and each was provided with a half-day training session, involving mock interviews. To demonstrate confidence in their ability to work independently, all three were allowed to work out of their home and were encouraged to set up the interview appoint-

ments on their own. However, they were informed that a C.S.R.U. staff person was available to assist with the scheduling of appointments if assistance was desired.

3. Consumer-Researcher Employment in a Qualitative Evaluation of a Co-op Housing Project

The third research project for which a consumer-researcher was employed was a qualitative evaluation of the two co-op settings mentioned above. "Christianne," the only consumer-researcher of the six who had a degree in mental health, was similarly provided with a half-day training session, permitted to work out of her home, and encouraged to set up interviews on her own. However, her experience differed from the others in that she was shown the measurement instruments that had been administered to date and asked to provide feedback. She was instrumental in pointing out areas that might be emotionally upsetting and areas which were not addressed. It was mutually decided that she would take a more informal, qualitative approach to interviewing and that her evaluation would take the form of a personal journal of her informal interviews with tenants.

4. Consumer-Researcher Employment in the Evaluation of a Multi-Support Apartment Project

The development of a model multi-support apartment project provided the opportunity to employ a consumer-researcher from the proposal and planning phases of the project through to administration of the measurement tools to tenants when they first took up residence in their apartment. "Mary" was provided with one half day of training and interviewed tenants in the building within the first few weeks of their move-in date. She administered quantitative measurement tools similar to the scales administered in project 2 above.

All consumer employees were asked, and agreed, to participate in interviews to describe their experiences as consumer-researchers. As this study was conceived after these research projects were completed, consumers were reflecting on their experiences retrospectively. It would have been useful to have had consumer researchers keep a journal of ongoing insights as they went through the process. The interviews were conducted by the first author, a young female researcher, who may have been less threatening than an older male. Interviewees were given the option of coming to the hospital and meeting with the interviewer in a private office or having the researcher come to their homes to conduct the interviews. Two of the six opted for the latter arrangement. Interviewees were encouraged to be honest about their experiences and were given the option of using pseudonyms if they so chose. They were assured that the information they provided would not affect their future employment opportunities in the C.S.R.U. or elsewhere. They were also provided with a draft of their interviews before they were shown to anyone and were asked to read through them and correct any misinterpretations, add comments, and delete anything that they felt was too revealing (Appendix A). In this way their identities remained confidential. This process also ensured that the interviewer had understood the statements they made. Although a semi-structured interview schedule was used (Appendix B), interviewees were encouraged to deviate from the questions as they thought of things they felt were relevant. In addition, the interviewer used non-directive probes to encourage elaboration when

a simple yes or no response was given. Each interviewee was provided with remuneration for participation in this research.

Initially, the interviewer planned to tape record the interviews. However, upon the advice of one of the interviewees, the interviews were conducted without a tape recorder. This supports the suggestion in the literature that mental health consumers require time to develop trust in professionals (Lord, 1989). The decision not to use a tape recorder permitted a more relaxed interview situation and likely facilitated more honest responses. However, this procedure increased the likelihood of interviewer bias since it was often difficult to take down verbatim responses. The above procedure of allowing interviewees to read through their interviews and correct any misinterpretation of their comments may have minimized this bias.

Asking consumer interviewees to read through their interview transcripts and make changes as they saw fit did not result in substantial changes to the recorded data. Two individuals simply indicated that it "looked good," two made minor grammatical changes, and the remaining two each objected to a particular quote asking that it be re-worded to accurately reflect what they had said.

All suggested changes were made and the revised transcripts were then examined to identify the main themes related to the research questions; specifically, benefits experienced as a result of employment, special needs identified that may or may not have been taken into account, and effects on data quality. Subsequently the six consumer researchers were mailed a draft of the completed paper and were again invited to provide feedback. No changes were suggested as a result of this latter procedure.

RESULTS AND DISCUSSION

The research study described in this paper was conceived after the six consumer employees had completed their employment in the C.S.R.U. Unfortunately, we were unable to obtain data during their actual period of employment. The results described here are based on retrospective reflection on the part of these six consumer employees. Although some of the findings apply exclusively to consumers employed as researchers in the mental health field, most are equally applicable to consumers who are employed in other capacities in the mental health field, such as service planning and delivery.

Labels

Although we have used the term "consumer" throughout this paper, this is not the term preferred by the individuals interviewed in this study. Nola stated that she preferred to avoid the use of labels altogether and described herself as "an individual who had used mental health services." Allan preferred the term "mental health consultant on consumer/survivor perspectives" since he had not been taking medication or seeing a psychiatrist for some time. Mary wondered when she would be able to stop calling herself a consumer. Christianne opted not to identify herself as a consumer and simply told the people she interviewed that she was a C.S.R.U. staff member.

Improved Quality of the Data

It was suggested in the literature review that interviewees are more at ease when interviewed by a peer (Finch, 1984). Five of the consumer-researchers disclosed their own history when they conducted the research interviews or administered the research tools. They felt the research participants were more at ease and probably provided more honest responses as a result. However, Allan observed that the residents he surveyed "did not respect him." Similarly, Jenny stated that some of the people she surveyed were "letting it all hang out" because they knew she too was a survivor. She felt that they would have been more cooperative if they thought she was a professional. It would not be ethically appropriate to require that a consumer-researcher disclose his or her history. However, some of the individuals interviewed in this study felt that disclosing their history resulted in increased rapport with the individuals they interviewed. On the other hand, both Allan and Jenny observed that disclosing their history resulted in a lack of respect and less cooperation.

Personal Benefits

As has been suggested in the literature (Kopolow, 1981; Pape, 1988; Wilson et al., 1990), most of the consumer-researchers reported increased self-esteem and felt they had been educated as a result of their employment. Nola learned "how to negotiate," "to be diplomatically assertive," and "to separate work and home life." Allan "learned about his own needs," "gained research skills," and "felt more confident about his abilities." He also learned "to ask for support from future employers." Mary "learned how to be part of a panel."

Remuneration

Each consumer employee was paid an hourly rate equivalent to that paid to non-consumer research associates. Although all six interviewees noted that they appreciated being paid for their work, Mary pointed out that "a professional would have been paid more to do the same work." While Mary "didn't expect to get a professional salary," she noted that the differential made her feel that her work was "less valuable." She felt that the type of work she was doing was "worthy of a good salary." Nola felt the pay was adequate but would have liked to have been provided with a benefits package "like other staff."

Empowerment

It is suggested in the literature that consumers are empowered when they have legitimate decision-making power, are involved through the entire research process, and ultimately effect the policies of their employing agencies (Church & Reville, 1989; Everett & Steven, 1989; Minister of National Health and Welfare, 1988). In the present study, three of the consumer-researchers (Nola, Mary, and Christianne) were involved in, and encouraged to provide input throughout the entire research process. They also had an affect on design, implementation, analysis, and final write up of the studies they were involved in. Nola noted that "it felt really good" when she said something wasn't going to work and, as a result, it was changed. Mary noted the committee with which she worked "encouraged her to express her opinions" and "really listened to what she had to say." Christianne

felt she was treated "like a professional" by her supervisor. Although all three felt their involvement had an impact, Nola didn't always feel free to express what she was feeling and she worried that her report was "sitting on the shelf collecting dust."

Allan, Jenny, and John, by contrast, were hired mid-way into their study and were simply asked to implement quantitative measurement tools. All three felt "it would have been a better experience" if they had been involved in the design stages of the research and they "would have liked to have seen the results." Despite these limitations, both Allan and Jenny felt their work had an impact on the department's policies.

There were some difficulties noted in the area of professional-consumer relations. Nola had difficulty participating in discussions that went on at coffee break, lunch time, or after work since she did not feel she had the "skills or permission" to be in a collegial relationship and she felt many of the staff were "superficial and socially distant." However, she recalled one staff person who really tried to "bridge the gap" by admitting that she too had difficulty writing formally and, on another occasion, asked for Nola's advice. Nola "really appreciated being invited to the staff Christmas party and being involved in the gift exchange," but she was disappointed that they didn't have a going-away party for her "like they did for other staff." She felt some staff were uncomfortable when she tried to share her insights because she was "supposed to be a colleague, not someone who could identify with the client." Jenny, Allan, and Christianne all felt it would have been easier to develop collegial relationships if they had been provided with an office in the hospital.

It is important to note that many of these findings are not unique to consumers. For example, it is likely that anyone who was hired on a temporary basis to conduct research out of his or her home would have difficulty feeling connected with other staff in the department.

Support

In outlining what he calls the empowerment model, Rappaport (1981) calls attention to the dialectic between respecting the rights of the individual to control his or her life and ensuring access to needed services. The results of this study suggest that we erred on the side of offering too little support. Two of the six interviewees, Allan and Jenny, were unable to complete the research task due to a recurrence of their mental health problems.

Wilson and her colleagues (1990) discuss the danger of consumer-employees becoming emotionally overinvolved with their "clients" which can lead to high levels of stress. Allan found himself "over-identifying with the residents' needs" and became "quite upset" about things that were unrelated to the research. In retrospect, he felt he should have asked for support, but noted that it was difficult to do so because he was "only in contact with his supervisor by telephone" and "felt ashamed about letting everybody down." He suggested that future consumer-employees "be required to spend a minimum of one day a week in the department" and "have regular face-to-face contact with their supervisor." He also suggested they "be given explicit permission to ask for emotional support for personal problems" and that the job be presented as "a training experience."

Jenny talked about the problem of negative memories surfacing when she interviewed people with similar histories. She felt that "as a professional" it was her responsibility to ask for support, but she found it difficult to do so because she was involved in "so little dialogue" with her supervisor. Nola described an experience very similar to Jenny's. She frequently encountered situations in the hospital that produced "painful memories," but felt "tremendous pressure to perform" and thought that asking for support for personal difficulties would have been viewed as "unprofessional." Nola also complained about a "lack of consistency" with one professional inviting her to come to her for emotional support and then being unwilling to provide it.

Like Allan, Christianne found it difficult working out of her home and would have preferred to have "an office in the hospital" and "more direct contact with other staff." Mary, by contrast, had a lot of direct contact with other committee members and stated that "there were several people to whom she could turn for emotional support" had she needed it.

Other Needs

The individuals interviewed in this study confirmed that receiving positive feedback on their work and having their contributions acknowledged, were important components of a positive work experience (Ridgway, 1988; Smith & Ford, 1986; Wilson et al., 1990). All six interviewees noted that their contributions had been verbally acknowledged. Nola added that feedback was very important since she sometimes wondered if her professional colleagues thought her ideas were "stupid or irrelevant."

The suggestion that adequate training is essential for successful consumer involvement (Wilson et al., 1990) was also supported by this study. Nola noted that she was required to perform tasks such as "writing memos, taking minutes, interviewing, and writing formal reports with little or no instruction." Jenny stated that she would have "liked some sort of training for dealing with uncooperative participants." Similarly, Allan felt he should have been provided with training on "how to handle different personalities." John noted that he needed some help developing his research skills and would have "liked some help scheduling appointments." Mary and Christianne both felt they were provided with adequate training.

The results of this study also support the use of flexible hours for consumer-employees (Pape, 1988; Wilson et al., 1990). Nola felt it was important that consumer-researchers "be allowed to graduate to full-time hours, particularly if they were not used to working." She also felt consumer-researchers should be allowed to work flexible hours and "should be given permission to miss a meeting for emotional reasons if necessary."

CONCLUSION

The results of this study confirm that, like most new employees, consumer-employees require adequate training and remuneration, feedback on their performance, and opportunities to provide input and effect decision making. When employing consumers or non-consumers as researchers it is important to involve them through all stages of the research process. A need that may be unique to consumers

is the need for emotional support for personal difficulties, particularly when their job involves contact with other consumers.

Apart from the above needs which are identified in the literature, the present study revealed three additional needs that should be considered when employing consumers. To begin with, it is important to facilitate the development of collegial relations between consumer and non-consumer staff. Second, consumer employees should be provided with an office space and opportunities for regular face-to-face contact with their supervisor. Finally, when employing consumers as researchers, their prior research experience must be considered. In the event that they have little or no previous research experience, the work should be presented as a training experience. Although it may be difficult to address all of these needs due to fiscal restraints, involving consumers without considering their needs may do more harm than good.

Our findings also confirm the assertion in the literature that consumers experience many personal benefits as a result of their employment as researchers. Benefits noted by the interviewees in the present study included: financial reward, education, the development of vocational skills, and increased self-esteem.

This study did not examine in detail the effect consumer-researchers have on the quality of the obtained data. However, all of the interviewees felt their identity as a consumer improved rapport with the people they interviewed or surveyed. Although it is not ethically appropriate to require such disclosure, the effect on data quality is an interesting research question. The results of this study suggest that, for some, the potential costs of disclosure, which may include a lack of respect and cooperation from the interviewees, may outweigh the potential gains of increased rapport.

Although it is not possible to conclude with any certainty that the consumers who participated in this research expressed their true feelings about their employment experiences, in light of the number of negative comments that were freely expressed it seems reasonable to conclude that the procedures of ensuring confidentiality, offering the use of a pseudonym, and guaranteeing that future employment opportunities would not be jeopardized, were effective at ensuring honest responses. Nonetheless, it is possible that the interviewees were somewhat guarded in their answers since the interview was conducted by a professional staff member from the department in which they were employed.

The study described in this paper could also be evaluated to determine the extent to which the principles of consumer participation were followed. The six consumer-researchers were not invited to participate in designing the semi-structured interview, or given the opportunity to participate in the collection or interpretation of data or writing of the final report. However, they were provided the opportunity to give feedback on their interview transcript and on an early draft of the paper. Since the feedback obtained on these two occasions was minimal, it might indicate that they did not experience ownership of the data due to their lack of involvement in other stages of the research. In that sense we fell short of putting into practice the research approach we advocate in this paper.

On the other hand, the study findings were presented at two professional conferences. In both cases, the consumer researchers were invited to present the paper with us. Since one of the conferences was out of province, we were only able to

invite three of the six due to budget constraints. However, all consumer-researchers were invited to present the paper with us at the second conference which was held locally. In addition, their input to this paper was acknowledged on the final draft, anonymously or by name according to their preference.

This research is important in that it documents the process of involving mental health consumers as researchers and suggests pitfalls to be avoided by other agencies which are planning on employing consumers. However, as noted by one of the interviewees, it is vital that such feedback be used to make changes in the employment arrangements for future consumer employees.

RÉSUMÉ

Le but de cette recherche était d'étudier l'expérience de six bénéficiaires de services en santé mentale qui ont été impliqués comme chercheurs rémunérés dans le domaine de la santé mentale. Des entrevues semi-dirigées ont été menées auprès de ces personnes en vue d'identifier tout bénéfice qu'elles ont pu retirer de leur emploi et les besoins spécifiques qui devraient être pris en compte quand on emploie des bénéficiaires. Bien que les bénéficiaires aient senti qu'ils avaient profité de leur emploi, plusieurs besoins non comblés ont été relevés. Les résultats de la recherche confirment aussi bien les bénéfices retirés par les bénéficiaires en santé mentale qui furent employés comme chercheurs que la nécessité de leur fournir des occasions significatives leur permettant de donner du feed-back sur leur expérience.

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