

Mental Health Consumers as Public Educators: A Qualitative Study

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Le présent projet de recherche qualitative a documenté le phénomène de l'intérêt, c'est-à-dire le sens subjectif de la participation des usagers dans les cours des étudiants au secondaire. L'objectif de cette étude était double : premièrement, découvrir le sens des différents vécus à travers l'analyse des descriptions faites par les participants et deuxièmement, documenter le processus pas-à-pas de la conduite de la recherche qualitative en sciences infirmières. La collecte de données incluait les observations sur le terrain, les entrevues semi-structurées, les questions ouvertes et les observations de six clients-participants atteints de graves troubles psychiatriques. Les entrevues ont été enregistrées au magnétophone et couchées sur papier. Toutes les observations sur le terrain et les entrevues ont été transcrites mot à mot. Les techniques de parenthésation, d'intuitionnisme, d'analyse et de description ont été employées pour identifier et rassembler les unités de sens naturel et pour synthétiser le(s) sens focal(aux) (Banonis, 1989). Les phénomènes importants sont les suivants : expérience positive, amour-propre rehaussé et introspection. Les résultats de cette étude confirment que la collaboration entre les infirmières et les usagers peut avoir une influence positive sur la guérison du participant atteint de maladie mentale.

This qualitative study documented the subjective meaning to mental health consumers of participation in high school students' education sessions. The purpose was two-fold: to uncover the meaning of human experiences through the analysis of participants' descriptions, and to document the step-by-step process of conducting qualitative nursing research. Data collection included field notes, semi-structured interviews, open-ended questions, and observation of six mental health consumers with major psychiatric illnesses. Interviews were recorded in both handwritten and audio forms. All field notes and interviews were transcribed. Techniques of bracketing, intuiting, analyzing, and describing were employed to identify and cluster natural meaning units, and to synthesize the focal meaning(s) (Banonis, 1989). The key phenomena were: positive experience, increased self-esteem, and introspection. The results indicate that a collaborative relationship between nurses and mental health consumers can be a growth-promoting experience for the consumers.

Consumer participation is increasing within all aspects of the mental health system. (The terms *consumer*, *participant*, and *user* are used interchangeably in the current paper to refer to an adult who is receiving treatment for a diagnosed psychiatric illness.) Consumers and health care professionals are working together as part of a growing movement toward consumer empowerment. Hutchison, Lord and Osborne-Way, (1986) addressed the concerns of consumers and offered strategies for increasing their participation; these included building non-professional peer networks of support, and accessing community resources. Church and Reville, (1989), discussed relevant issues such as unbalanced power relationships and organizational entrenchment. A first

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step in reducing obstacles to equitable power relationships is to identify consumers who are willing to discuss the problems they experience within and outside the service system. The June 1989 issue of Canada's Mental Health was dedicated to consumer issues. Increasing numbers of consumers are actively involved in program planning, have an input on committees and boards at hospitals, and are affecting decisions that determine future policies.

Although there are considerable political and social pressures to increase the involvement of consumers, there has been little or no research to investigate the impact that such involvement has on the consumers themselves. As noted by Church and Reville (1989), user involvement in Canadian mental health services is in an embryonic stage and existing initiatives are generally undocumented. The current study gathered information about the experiences of consumers who spoke to Grades 11 and 12 high school students as part of an educational forum, entitled "Beyond The Cuckoo's Nest". The purpose of the program was to increase the students' knowledge of mental health and psychiatric illnesses, and reduce negative attitudes toward the mentally ill. Professionals and consumers worked in partnership as educators of the students. The educational methods used were observational, didactic, experiential, and interactional (Mound & Butterill, 1992). During the teaching session two or three consumers described the experiences and situations they faced as persons with a psychiatric disability. They talked with the students informally about how they had dealt with their illnesses, and responded to students' many questions about their difficulties. These sessions had been conducted by the investigators at the Continuing Care Division of the Clarke Institute of Psychiatry, in Toronto since 1988.

Initially, consumers were informed about the purpose of these educational sessions and invited to sit in and observe. If they expressed interest in participating, mock teaching sessions were held with a nurse case manager. These rehearsals helped consumers to attain the comfort level needed to interact with students in an educational forum. The actual sessions took place in the hospital auditorium with 100 to 200 students and their teachers. Each consumer spoke with the students for about 25 minutes. Some consumers participated once or twice, but many volunteered to participate on an ongoing basis. One consumer brought her children, some invited other consumer friends, and others invited their parents. Three investigators participated in and observed many sessions of this education program. After completing the first year, the researchers' impressions were that these experiences had a positive influence on, and were important to the consumer themselves. However, at this point, understanding of the phenomenon was limited by the anecdotal nature of the evidence. Plans to continue these forums provided the opportunity for a more systematic and thorough investigation.

Purpose and Research Question

The purpose of this study was to increase understanding of the influence on consumers of their participation in educational sessions, to tap directly their expertise and experience, and to describe and evaluate the meaning of their participation. The research question was: What is the meaning of the experience for consumers who participate in public education?

Method

The goal of our study was to uncover the meaning of human experiences through the analysis of participants' descriptions (Parse, Coyne & Smith, 1985). In other words, the investigators were concerned with the "what" and not with the "why" (Kruger, 1981). A phenomenological qualitative research method was chosen because it was best suited to document and interpret the "totality" of consumer participation in the educational sessions from the participants' viewpoint or frame of reference (Leininger, 1985). The experiences of the participants were explicitly considered by using their oral descriptions, and these constituted the raw data (Parse, Coyne & Smith, 1985).

Study Sample

The sample consisted of 4 males and 3 females between the ages of 31 and 45. All had a primary diagnosis of a long-standing (10–20 years) schizophrenia or bipolar affective disorder and were receiving ongoing outpatient and intermittent inpatient treatment in the Continuing Care Division of the Clarke Institute of Psychiatry, where the investigators were working as case managers. In addition, some of the participants had a dual diagnosis of substance abuse. Consumers were encouraged to volunteer to participate in the research project because positive relationships already existed between the consumers and investigators. Potential candidates constituted an opportunistic sample (Field & Morse, 1985): they met the criteria of speaking English, had participated in the high school students' educational sessions a minimum of three times, and had the ability to verbally describe their experiences, thoughts, and feelings. The sample size was kept small because each participant created a large amount of verbal data that had to be transcribed verbatim and analyzed (Sandelowski, Davis & Harris, 1989). One of the seven individuals withdrew from the study and from the educational sessions. Unfortunately, he did not share his reasons for withdrawing and declined to be interviewed.

Participants were given a clear explanation of the nature and purpose of the study and how the data would be collected. They were informed that there was a time commitment, that their participation in the educational sessions and in the study were voluntary, and that in no way would their participation influence their individual psychiatric treatment. They could withdraw from

the study at any time and continue to participate in the educational sessions if so desired. Only the investigators would know the identity of participants; their right to confidentiality would be protected by using their initials. After the data analysis was completed the tape recorded interviews were to be erased. Participants were warned that they might experience some anxiety with the disclosure of feelings related to personal experience. On the other hand, they were told they might benefit by the knowledge that their input could contribute toward increasing understanding of consumer participation in public education. A written consent was signed by each participant and, prior to data collection, a comprehensive research proposal was submitted to the Institute's Research Review Committee on the use of human subjects. After some initial modification, the proposal was re-submitted and the Review Committee approved the study. The nature of the data collected did not require the use of the subjects' medical charts.

Data Collection

Participant observations and semi-structured interviews were conducted with three female and three male consumers at mutually agreed upon times. Each investigator conducted two one-to-one interviews. The researcher socialized with the participant at the beginning of each interview, to establish a rapport with them (Kruger, 1981). Open-ended questions were asked to explore the consumer's own perceptions of the audience and their reactions during the public speaking experience; participant's satisfaction with the presentation; and the meaning that verbal, written, and general feedback had for the participant. The following types of open-ended questions were used: What has it been like for you to participate in the educational sessions? Why have you participated in the educational sessions? What was your general impression of the audience? What do you think the reaction of the audience was to your presentation? How did your participation influence the audience's attitude towards psychiatric illness? How do you feel about reading the feedback on the evaluation forms? In what way does the feedback change your image of yourself? What factors would discourage you from participating or encourage you to participate? These exploratory open-ended questions helped to probe the benefits and disadvantages of participation as perceived by the consumers, and provided adequate flexibility for them to expand on their experiences. If either the researcher or the consumer had difficulty in understanding what was said, the question was repeated without paraphrasing so that leading the participant could be avoided. Deliberate attempts were made to conduct the interviews in an informal and non-directive manner aimed at minimizing the interviewers' influence on the participants (Kruger, 1981).

The interviews were recorded in both handwritten and tape-recorded form and subsequently transcribed. The use of tape-recordings enhanced the

accuracy of the transcripts (Field & Morse, 1985). Investigators employed the techniques of bracketing and intuiting during the data collection process. Bracketing refers to the technique of laying aside assumptions to allow the lived experience to be seen (Oiler, 1982). The investigators disciplined themselves to keep original assumptions and judgements separate in order to remain open to the emerging data. Although it is impossible to be totally free of bias, this technique helped reduce bias. Intuiting refers to the process of coming to know the phenomenon from the participant's perspective (Parse et al., 1985) so that the investigator is looking at the experience with wide-open eyes. This required concentration and strict adherence to the surfacing meaning, and involved openly looking, listening, and feeling in order to ascertain the uniqueness of the phenomenon of interest (Parse et al., 1985), in this case, consumers' participation in public education sessions. Thus, empathic and intuitive modes of awareness were deliberately and purposefully employed in the data collection (Oiler, 1982).

Field notes were meticulously recorded immediately after the interviews to ensure accurate recall of the contextual factors, because social situations influenced the content of data collection (LeCompte & Goetz, 1982). These notes recorded the investigator's thoughts and feelings about the interviews, including the effect of the investigation on the participant, observations about their verbal and non-verbal behaviour, and contextual factors.

Data Analysis

Skodol Wilson (1985) defines analysis as the process of separating data into parts for the purpose of answering the research question and communicating the answer to others, mainly in narrative, rather than in numerical form. The investigators sought to achieve group consensus throughout all aspects of the data analysis by individually and collectively reviewing and analyzing the transcripts, and discussing emerging concepts/categories. After data analysis, the validity of the findings was checked with participants to ensure that their perspectives were portrayed accurately. Such rigor was necessary to ascertain that the findings reflected the described phenomenon and had been clearly articulated. Burns and Grove, (1987) define rigor as the striving for excellence in research, associated with discipline, scrupulous adherence, and strict accuracy.

A narrative text was accumulated from the written field notes and transcribed interviews. Prior to transcribing the tape-recorded interviews, investigators alone and afterwards, together, replayed the tapes and listened attentively to participants' responses (tone and volume of the voices, pauses, hesitation, etc.) to the open-ended questions and also to the content of what was described, and compared these with the interviewer's notes. Changes in voice tone, significant pauses, and laughter were noted on the tapes. After inter-

views were transcribed, each investigator checked and corrected the transcripts of her own tape-recorded interviews and inserted notes and comments in the margin. One copy of each of the six transcribed interviews was secured in a safe place against loss, and one copy distributed to each investigator.

Bi-weekly meetings were held for investigators to analyze the data. Each transcript was read and re-read to allow the researchers to become familiar with the data. The techniques used to gain some understanding about the meanings of each participant's experiences were contemplative dwelling (Parse, et al., 1985), the undistracted repeated reading of the transcript, along with intuiting, analyzing, and describing. This process allowed the researchers to identify and cluster natural meaning units or scenes (Banonis, 1989, p. 39) in the transcript. Clustering is the grouping together of related events, processes, or settings to gain better understanding of the phenomenon (Woods & Catanzaro, 1988).

Unsuccessful attempts were made to use the large margins of the transcript and coloured highlighter pens to note the common descriptive expressions and recurring elements of the data (Field & Morse, 1985). Both methods proved to be inadequate to manage the large volume of data. Therefore, the investigators developed their own data sorting method (Field & Morse, 1985). Initial broad concepts/categories were identified and written on separate sheets of full-size writing paper. According to Burns and Grove, 1987, a concept/category is a word or idea to which abstract meaning is attached. Investigators then studied each participant's description, writing all natural meaning units – descriptive expressions, persistent words, phrases, and paragraphs – under the initially identified broad concepts/categories. A descriptive expression is a statement that completes an idea about the lived experiences (Parse et al., 1985). This method was found to be stimulating, and facilitated data sorting. After collecting all significant words, phrases, and descriptions from the six transcripts, the investigators eliminated the statements, phrases, and words, in each identified concept/category that communicated similar meaning (Parse et al., 1985). After the data were collected and analyzed, investigators conducted an extensive computer-aided literature search. In phenomenological investigations the literature review is delayed to ensure that the study is truly grounded in the data (Cobb & Hegemester, 1987), so that information in the literature does not influence the researcher's objectivity (Burns & Grove, 1987).

Findings and Discussion

Eight common elements or broad concepts/categories emerged from the data: respect, acceptance, new role, self-esteem, commitment, stigma, self-reflection, and altruism. The following direct quotations from the transcripts capture the meaning of the eight concepts/categories.

Respect. Participants talked about their positive experiences in the educational sessions with the high school students. They perceived respect from the students that was expressed verbally and behaviourally:

"I was given the opportunity to say my piece without interruption. The students showed respect, they were interested in knowing about me..."

"...liked the audience's reaction, they were nice to us, they didn't call us mental patient or psycho or anything like that. They just see that we're down to earth people like everybody else."

"...and I got praised about standing up on stage and talking...I think they picture us as not just ex-psychiatric patients but as people who have lives outside of here, with their jobs and family."

Acceptance. The following quotes from the consumers were clustered under the category of acceptance:

"They seem to react pretty well to what we had to say. They expect to find people who looked mentally ill...They expect to find people who are different from them and then they find out that we're not. I think they were pleasantly surprised about how we appear and how we present ourselves."

"...they didn't make me feel like an outcast. I was accepted. I felt wanted and cared about by the students. Their reaction made me feel that I wanted to come back."

"The students were attentive. They take to heart what you say to them... they made me feel at home."

New Role. Participants referred to themselves as teachers of the students. They clearly identified a new role for themselves that was different from the traditional patient role:

"I was educating the students by telling them what happened to me. I participated in the sessions to promote awareness about lack of education in mental illness."

"Before teaching the sessions I would think about what I was going to be saying in a coherent form, that it makes sense to the students."

"...it gives you a really good feeling to know that what you are doing is educating, giving people a better insight."

Self-esteem. Consumers gave a positive account of their experiences. They used feeling words to describe the challenge of participation in public education, and its impact on their self-esteem:

"...I felt pride! They [students] told me I have done quite well. Delivering those talks to the high school students made me feel worthwhile."

"I have never before gotten in front of a group of high school students by myself and just talked to them. I felt like I achieved something. It boosts my ego definitely, because my ego isn't very good."

"I felt satisfaction, doing it [teaching]. I suppose in reflecting on myself, it reflects that I am a positive and intelligent person and do a good job."

Commitment. Participants were favourably influenced by their experiences; what they were doing was important to them and to the students. They valued their participation, became interested in continuing, and described commitment to their teaching activities:

"I had to quit the sessions to go to work but every once in a while I will take leave of absence for one morning so that I could attend the teaching sessions."

"I do it [teach] twice a month because I am aware of the lack of education. I would do it [teaching] whether there was an honorarium or not, because work is healthy, and it's a sense of responsibility to those kids."

"I just want to, as you say in the sessions, debunk some myths about mental illness because I live in this society and whether it is good or bad, I am still in it...so the better it is, the better I am off. I can't think of anything that would discourage me from participating."

Stigma. Consumers increased their visibility while working collaboratively with mental health professionals. They talked about the stigma of being a mental health consumer and its impact on them. They described a strong desire to reduce the stigma by humanizing their experiences through their participation in public education sessions:

"We are not just labels...but people behind the labels. I want to do my bit to relieve [the] stigma of mental illness in our society."

"My example of stigma is loss of jobs because of psychiatric history. Just try, just try to find a job when you have to put details of past employment and why you were off when you apply for a job – and after you have tried that – you will have the answer about stigma."

"[The] stigma is less with educated people; it's more from the older people...the stigma in society is atrocious and even relieving a tiny bit of it would be instrumental in helping."

Self-reflection. Participants were willing to share personal experiences of mental illness with the students, and this was rewarded by positive feedback from the students. This process allowed consumers to look at themselves from a different perspective. They began to look inward and described their experiences:

"I spoke from my heart and my soul. It [teaching] helps with my self-examination about my morals, my gripes with my illness as well."

"This experience [talking with students] makes me kind of reflect on what it has been for me to be a schizophrenic from the very first symptoms to today, working and living with it, and also talking about it."

"We have problems that are different from their [students] problems, but on the whole, we have the same aspirations and goals like making money, having a good laugh, having friends, having a job. They see that we have just the same hope as them."

Altruism. Consumers described their commitment to educate the future generation and change societal views of mental illness. They reflected on their social conscience and unselfish attitudes:

"If I can help one person out there, it would have been helpful, useful, worth my while."

"I don't want them [students] to go through what I've been through ...hope that they don't make the same mistakes or even if they do, there is hope."

"...because I am concerned that maybe one or two of those kids are going to have mental illness and they are not going to know what to do and maybe my experience will help them."

Conceptual maps of the findings were constructed based on the eight broad concepts/categories identified. Investigators linked the eight categories and their attributes (Figure 1), and identified the focal meanings of consumers' experiences that described the phenomenon.

Figure 1

Linking of eight broad categories

• respect	• acceptance	• new role	• commitment	• self-esteem	• stigma	• self-reflection	• altruism
Positive Experience		Increased Self-Esteem			Introspection		

A second version of the conceptual map was constructed (Figure 2) to help demonstrate more clearly the interactive nature of the process through which the synthesized meaning of the study emerged: positive experience, increased self-esteem, and introspection.

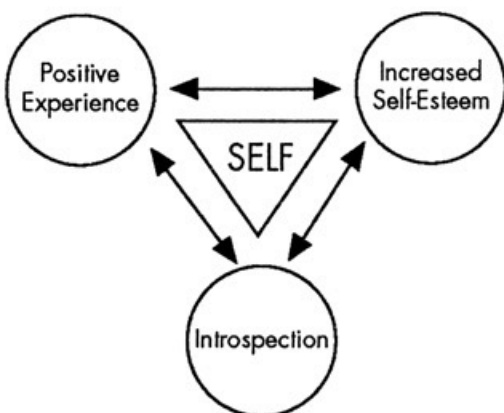


Figure 2

Synthesized focal meanings

Consumers repeatedly described the positive experiences associated with their participation in public education. They referred to the respect, acceptance, positive feedback, interest, and encouragement they had received from the students, and to the fun they had experienced. Such positive reinforcement from the students greatly influenced consumers' feelings about themselves and their performances. They described feelings of pride, achievement, and satisfaction, summarized by one of the participants as: "...All the positive stuff, incredible how much positive feedback I got. It's really encouraging ...They said the highlights of the sessions were my thoughts, ...I felt pride... I felt valued by the students." Participants described their new roles, as public educators: "It was challenging and satisfying,...It was uplifting...It made me feel that I wanted to come back." They attached personal value to their input and committed themselves to education: "My main reason for participating is to teach the kids,...this generation should be better informed." Participants shared their perception that the stigma of mental illness is less common among educated people. "I have suffered from misunderstanding and people not wanting to know anything about my condition." They felt optimistic about their influence on the future generation and expressed a desire to create a better society.

As participants became more comfortable in articulating their experiences, the encounter between consumer and audience deepened. Self-disclosure of subjective experiences not only informed the students about mental illness, but led the consumers toward an internalized process which the investigators referred to as introspection. Communicating about an illness that was deeply felt uncovered intense emotions and personal meanings: "This is deeper, it's my deepest experience of my own being which is not my soul, but the second deepest thing which is my illness, and communicating and explaining how I deal with it and how I don't deal with it."

Consumers talked about their need to communicate the pain and anguish they felt. They related the pain not only to the trauma of the acute phase of their illness, but also to the suffering they experienced in living with a long-term mental disability: "I shared my experiences of pain and being different...they saw what it is really like." Participants, by revealing their pain to the students, not only gained insight into their own world of mental illness, but created a profound experience for themselves, transforming former devastation into an experience of personal growth.

Participants' descriptions of their experiences signalled the beginning of a process of personal growth by transcending the devastating effects of illness. The investigators believe that depth of the experience, personal growth, and optimism for the future are elements crucial to the person's recovery. This recovery process affects the dimension of wholeness within the person.

Participants discovered meaning in relating their personal experiences of the illness. Although the illness remained, they became engaged in a growth process through self discovery as opposed to becoming entrenched in the sick role. As Haines (1986, p. 119) states: "The concept of total rehabilitation encompasses the building of meaning into the recovery process which exceeds the isolated restoration of bodies and minds."

To the best of the investigators' knowledge, no published studies exist that address consumers' participation in public education and the impact of such experience on consumers. However, numerous studies in the literature have shown that negative portrayals of mental health consumers in the media reinforce the stigma of mental illness, and that education (whether formal or public) helps to reduce the stigma. Wahl and Harman (1989) surveyed 487 members of the National Alliance for the Mentally Ill (NAMI) in 20 states. The majority of participants identified stigma as a concern for their families and for their mentally ill relatives. Media depictions, film portrayals, and news coverage were seen as significant contributors to the stigma. Provision of factual information about mental illness was helpful for reducing stigma. Hyler, Gobbard, and Schneider (1991) also showed that movies and television programs contributed to the development of society's negative attitude and stigmatization of the mentally ill persons. The authors claimed that "helping to bring the etiology of stigmatizing stereotypes to public awareness constitutes an important service to the public" (p. 1048).

In a survey of 514 people in Finland, Ojanen (1992) concluded that older, less educated people had more negative attitudes toward the mentally ill than did younger, more educated people. Page (1983) reported that persons who made reference to their mental illness or hospitalization were prejudiced against and less successful in obtaining housing. Desforges and colleagues (1991) based their study on the hypothesis that contact with a stereotyped, stigmatized group member positively effects prejudiced students' attitudes. Undergraduate students participated in learning sessions with confederates who were depicted as former mental patients. It was found that after the study session, initially prejudiced attitudes had changed to more positive ones.

Mansouri and Dowell (1989) noted that education of the long-term mentally ill was associated with decreased perception of stigma and that attitudes were linked to self-concept and psychological distress. The authors suggest that: "Programs that create a nonstigmatizing environment can successfully reduce the perception of stigma of the participants" (p. 89). Todres (1989) described a self-help Toronto-based clearinghouse as a community-based model of service delivery characterized by marked participation of the mental health consumer. The model emphasized face-to-face social interactions and educating the community about the value of mutual-aid/self-help

groups. Everett and Steven (1989) examined barriers to consumers' participation in a high-support housing research project. They addressed strategies for minimizing barriers between professionals and consumers. Consumers concluded that their experience was positive; they gained knowledge about different types of housing and identified new skill areas that contributed to their increased self-confidence and self-esteem. Peterson (1986) described a successful psychosocial rehabilitation program offered by a rural clubhouse. Patients were integrated into the community by training them to assume alternative roles and build the new roles into a positive self-concept. Clark, Goering, and Tomlinson (1991) gave account of clients' positive response to role demands, challenge, activity, and normalizing expectations.

Francell (1994) in his editorial poses the question: Why have attitudes changed so slowly in spite of the tremendous growth in advocacy for persons with severe mental illness? He asserts that changes in terminology are needed to increase public awareness: "A patient who has schizophrenia or manic-depression should not be described as 'mentally ill' but [as] having a neurobiological disorder" (p. 409). He advocates increased public education and awareness efforts to improve the lives of people with neurobiological disorders.

Conclusion

In the current paper, the authors presented a phenomenological study of six mental health consumers who had shared their knowledge and personal experiences with high school students. The qualitative research techniques of bracketing, intuiting, abstracting, and describing were used to cluster data into categories/concepts or natural meaning units that were further synthesized to describe the focal meaning of consumers' participation in public education. Conceptual maps helped to identify the subjective experiences of consumers as public educators: positive experience, increased self-esteem, and introspection. Empowerment of consumers occurred as they described their own experiences and became adept at interacting with the audience of high school students. They took on a new role as the educators of the public and became interested in an ongoing teaching/learning experience with the high school students. Their participation became purposeful as they shared their experiences and knowledge of coping with mental illness. In return, they gained respect and acceptance from the students. These experiences prompted positive feelings and self-evaluation. In summary, by stepping out of the traditional patient role and becoming actively involved as program participants, consumers entered into a new challenging path towards their own recovery. Written evaluations from the students and teachers indicated that public education is a powerful intervention strategy for reducing stigma and stimulating awareness of mental health issues. An interview with the one individual who withdrew from the study might have contributed to a more balanced

view on the public speaking experiences. These findings clearly indicate that the participation of consumers in public education was a positive, growth-promoting experience. This was congruent with the researchers' earlier stated assumptions that these experiences had a positive influence on consumers. A collaborative relationship between consumers and professionals can lead to a mutually satisfying experience.

The impact of high school education events on lasting changes in students' attitude towards mental health consumers remains to be explored. In addition, the usefulness of the program as an adjunct to classroom teaching should be evaluated by teachers and curriculum planners.

The investigators found that the phenomenological paradigm was effective in uncovering the meanings for consumers of their participation in high school education sessions. The researchers hope that their description of the step by step process of conducting a qualitative phenomenological research project will benefit other professionals.

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