

✧ SCHOLARLY PAPER ✧

Consumer participation: Ensuring suicide postvention research counts for end users

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Consumer participation: Ensuring suicide postvention research counts for end users

Primary health-care research is about working with those who have a vested interest in the outcomes of that research, including consumers, service providers and service organizations. This article describes how consumers were included in the research processes of a South Australian study into suicide postvention services, and illustrates important principles to consider when including consumers in research. A concurrent mixed-method approach facilitated the collection of mixed data through the application of questionnaires. The study was conducted in an Australian metropolitan area. Because of media releases, a large number of people rang to enquire and volunteer their participation. From over 200 expressions of interest, 161 individuals participated. The participation of consumers in the research process ensured the findings were relevant for end users. A number of recommendations for the care and support of those bereaved through suicide were developed as a result.

Key words: consumer participation, primary health care, research, suicide postvention.

INTRODUCTION

Primary health-care research is about working with those who have a vested interest in the outcomes of the research. Interested stakeholders include consumers, health service providers and health service organizations. There is a need for consumer participation in health reform in Australia, but the complexities of our health-care system and of medical and health issues are not easy

for the community to understand. As a result, there is a perception among the community that they cannot contribute to health reform.¹ Nevertheless, consumers and the community have wide-reaching roles when involved in research. The National Health and Medical Research Council and the Consumers' Health Forum of Australia have jointly developed the *Statement on Consumer and Community Participation in Health and Medical Research*,² because many consumers and researchers recognize the contribution that consumers can make to research and their right to do so. The *Statement* is intended as a guide to consumer participation, at all levels and across all types of health and medical research in Australia. Consumer participation in research might include activities such as:

- Consumers contributing to setting the research agenda and the research questions

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The full report of this research, entitled, South Australian Suicide Postvention Project 2004: Report to Mental Health Services, is available from: <http://hdl.handle.net/2440/37903> (168 pages).

- Moving beyond the notion of informed consent to informing research participants about the outcomes of the research they participate in
- Ensuring that the community has access to research results
- Greater community involvement in research leading to greater interest from individuals in participating in research and greater support from the community for research²

It is evident that the roles of consumers can be varied from being participants in a study, advising on how to communicate with the community, contributing to establishing the research process, and advocating for consumers' rights and interests. This paper describes a South Australian study that included consumers in the research processes as both participants and advisors, and illustrates important principles to consider when including consumers in research. The study was underpinned by the belief that those who have experienced a phenomenon are best able to guide researchers during investigation and translate those findings into recommendations for practice.

A STUDY OF SUICIDE POSTVENTION

A two-year study seeking to examine current approaches to postvention services available for those bereaved through suicide in metropolitan Adelaide was conducted through the University of Adelaide, Australia, and funded by the South Australian Department of Health.³ Three key tasks were set to achieve this:

- To undertake an audit of existing postvention services
- To examine the needs of people bereaved through suicide
- To review the support and educational structures available for service providers of postvention services

To help in the classification of target groups, operational definitions were developed: suicide was defined as death designated as suicide by the Coroner, and bereaved persons were anyone bereaved as a result of suicide and included relatives, friends, peers and colleagues. Service providers were defined as health professionals and others providing health services and specifically included general practitioners, psychologists, psychiatrists, social workers, nurses, religious counsellors and volunteers. Organizations to be studied included government and non-government agencies, whose objectives included the care and support—practical, psychological, physical, social and spiritual—for people bereaved through suicide.

Research design

A concurrent mixed-method research approach was chosen because of its ability to address the project objectives within the given time parameters.⁴ This is a multi-strand design in which both qualitative and quantitative data were collected by the same method and analysed to answer a single type of research question. Ethics approval was received from the University of Adelaide Human Research Ethics Committee.

Community support

A high level of support for the research project was received not only from individuals, but also from community groups. For example, the Funeral Directors Association wrote to all their members asking that they support the study and assist by sending questionnaires to all members. Community radio was also extremely supportive by making announcements on ethnic radio stations and distributing information about the study. It was encouraging to receive such support from within the community.

Recruitment of consumers

As the study sought to examine the needs of persons bereaved through suicide, it was vital to hear directly from the people themselves. We had planned to advertise widely to recruit individuals for the study, but because of unexpected media releases in newspapers and over radio, a large number of people rang to enquire for more information and volunteer their participation. Because of such an enthusiastic response, it was decided not to limit the number of participants, nor refuse anyone who volunteered, as this was thought heartless in view of the degree of eagerness shown. From over 200 expressions of interest, 161 persons participated in the study. Table 1 shows

Table 1 Sources of information about the study

Source of information (<i>n</i> = 161)	<i>F</i>	%
Newspaper	75	46.6
Support group	40	24.8
Radio	21	13.1
Family or friends	18	11.2
Internet	6	3.7
Hospital nursing staff	1	0.6

the means by which participants found out about the study.

The recruitment process resulted in 172 (48.7%) questionnaires being received (total mailed $n = 353$), of which 161 (47%) were sufficiently completed to be included. No incentives were provided. The method of recruitment made provision for other than the immediate family to participate in the study, such as second-degree relatives, friends, workmates and colleagues.

Project reference group

In addition to those participating in the study, two consumers also contributed considerably as members of the research reference group with other health and research experts from the field. Bereaved through suicide support groups were invited to provide consumer representatives who had themselves experienced the suicide of loved ones. The reference group advised us for the duration of the project and, at completion, formed a consensus forum to develop project recommendations. Consumer representation provided a realistic perspective and offered insight into issues for the bereaved. This helped to make the research more relevant to people's needs and concerns, and led to outcomes that were reliable and more likely to be applicable to the existent situation.

Discussion forum

At completion of the study the project reference group, including consumers and other invited stakeholders, formed a discussion forum. The preliminary findings of the study were presented in the draft research report and circulated 10 days before the forum held for discussion of the findings. The forum acted as a validation process that allowed us to examine multiple levels of data and explore phenomena with specific reference to the participants. At the meeting, attendees were asked to discuss what the report revealed under the following three headings—*what is already there, what is missing, what is needed*. This information from the meeting was collated to form the recommendations.

Data collection

Self-enumerated questionnaires were developed, pre-tested and modified before being posted to those who had volunteered to participate. The questionnaires collected both numerical, statistical (quantitative) data and narrative text (qualitative) data. Accompanying the questionnaire was a letter of invitation to participate, an

informational flier and information about how to make a complaint. A project officer conducted the study on a half-time basis over 2 years, which allowed adequate time for data collection and follow up.

Questionnaire development

Topics for exploration in the questionnaire were determined following a literature review as well as by the personal local knowledge of the authors and members of the reference group. Following a search for existing instruments and personal communication with international postvention experts, a number of relevant task-specific validated questionnaires were obtained from overseas. Some required translation in order to ascertain their usefulness. A questionnaire from Norway⁵ was found to most suit our objectives and was officially translated. Questions were adapted and added to suit the South Australian demographic context and types of services and health professionals in Australia.

The questionnaire comprised three sections. The first related to personal information about the person completing the questionnaire, the second to information about the person who suicided (relationship, age, gender), and the adequacy of the support they received. The third section requested information about services the person received after the suicide. The type of questions asked included, 'did you receive any information about support services available to you after the suicide?' and 'were you offered assistance from any support services after the death?' Questions in section three also referred to bereaved children, community support received, the participant's personal experiences such as engaging in sport or work and the responses received from others following the death.

Both closed and open-ended questions were applied to maximize available information. The bereaved persons' questionnaire comprised 59 questions. The option for extensive, expanded written descriptions of individual's experiences was provided.

Overall, the bereaved persons' questionnaire aimed to determine the demographics of the respondent, establish relevant facts relating to the person who had suicided, determine their need for help following the death, establish and evaluate the usefulness of the services received (if any) after the suicide and provide opportunity for suggestions for improving support for the bereaved.

Data analysis

Quantitative data were analysed with the assistance of spss software for statistical analysis.⁶ Qualitative data were

thematically coded with the assistance of the software package QSR Nvivo2 according to the objectives of the study, as outlined earlier.⁷ The final inferences formed from the results were based on analysis of both sets of data. As it is the purpose of this paper to more broadly discuss the involvement of consumers as partners in research, readers are encouraged to source the full findings as published.^{3,8}

Ethical considerations

Principles of ethical conduct in human research were adhered to in accordance with the National Health and Medical Research Council recommendations: informed consent, confidentiality and beneficence.⁹ The University of Adelaide Human Research Ethics Committee gave approval for the study to be conducted. A database of persons volunteering to participate was drawn up and each assigned a coded number matched to a questionnaire. Questionnaires were de-identified and stored securely so that only the research team had access. An information flier about the study, informing participants of their rights, and a complaints form were posted with the questionnaire.

Risks and benefits

During the course of the project, every effort was made to minimize the risk of causing distress in a participant. Considered of benefit was that the researcher was an experienced community nurse with attributes considered desirable for working with 'sensitive' participants and experience in working with distressed persons. We recognized that the project was working in a personally sensitive area for individuals and every effort was taken to minimize the risk of causing distress in persons suffering reduced cognitive functioning through grief.^{10,11} Strategies included a list of counselling services and their contact numbers and hours of operation,³ sensitivity when communicating with participants and in data collection and acknowledgement that in exploring such issues participants might need support.

RESULTS

Profile of bereaved respondents

The minimum age of participants was 20 years and the maximum 78 years (median age 50 years; mode 43). Participants' demographic variables are portrayed in Table 2. Three-quarters of the respondents (75.6%) were women. Sixty per cent were in married or de facto rela-

Table 2 Frequencies and percentages for respondents' demographic variables

Variable	Level	F	%
(respondents N = 166)			
Gender	Male	40	24.4
	Female	124	75.6
Marital status	Married/de facto	97	59.5
	Divorced/separated	20	12.3
	Never married	22	13.5
Education	Widow/er	24	14.7
	Left school no further study	55	35.3
	In school/further study	9	5.8
	Trade qualification/apprenticeship	14	9.0
Employment	University/higher education	78	50.0
	Full time	51	31.3
	Part time	52	31.9
	Unemployed	5	3.1
	Home duties	24	14.7
	Retired	25	9.2
Culture	Student	6	3.7
	Australian	118	74.7
	English/Irish/Scottish	27	17.1
	European	9	5.7
	Asian	2	1.3
	Aboriginal/Afghan	1	0.6

tionships and the remaining 40% were fairly evenly distributed between the three categories of being separated or divorced, never married, and widowed. Half of the respondents had received University or higher education, a third had left school without further study and only small percentages were either still studying, or had received trade or apprenticeship training. Almost a third of respondents were employed full time and a further third were employed part time. The remaining third were either involved in home duties or retired. Only 3% were unemployed, with the remaining 4% being students. Almost half of the respondents were Health Care Card holders, indicating a low taxable income. Three-quarters identified as being from Australian culture. Another large group included those from English, Irish or Scottish backgrounds (17%) and only a few individuals came from various European, Asian or South African backgrounds. One subject identified as being Aboriginal/Afghan. For almost

Table 3 Frequencies and percentages for variables about the suicide

Variable (respondents <i>N</i> = 166)	Level	<i>F</i>	%
Times bereaved by suicide (<i>n</i> = 160)	Once	136	85.0
	Twice	15	9.4
	×3	7	4.4
	×4	1	0.6
	×6	1	0.6
Discovered the suicide? (<i>n</i> = 164)	Yes	23	14.0
	No	141	86.0
Present at site of suicide? (<i>n</i> = 164)	Yes	55	33.5
	No	109	66.5
Gender of deceased (<i>n</i> = 163)	Male	118	72.4
	Female	45	27.6
Age of deceased (<i>n</i> = 163)	14–15	45	27.6
	16–24	72	71.8
	25–34	36	22.1
	35–44	10	6.1

all respondents the main language spoken at home was English, which is consistent with the predominant cultural backgrounds. About a third of participants had children under the age of 16 years at home at the time of the suicide. The mean number of children was 1.7 (mode = 1; range 1–4).

Eighty-five per cent of participants had been bereaved once through suicide (Table 3). It is notable that 15% had lost two or more close people to suicide and that one had been bereaved six times. Fourteen per cent had experienced the trauma of discovering the suicide, and a third of respondents had been present at the site of the suicide, another very distressing experience. That three-quarters of the deceased were male was consistent with national statistics.¹² Nearly three-quarters of the deceased fell into the 16- to 24-year age group.

DISCUSSION

Many health consumers believe they have the right to participate in health and medical research, not simply as passive respondents or token representatives but as equal partners in the development of research goals, questions, strategies, methodologies, information dissemination and reporting.² In this way, research can better serve the

needs of health consumers and the wider community. A community that is more aware of current health research activities is also likely to provide greater support for research and researchers.

Consumer participation in research brings with it responsibilities for consumers and researchers. The reported study achieved this by:

- Being respectful of each other's knowledge, for example, including consumers on the research reference group as advisers
 - Sharing information with each other about research issues such as having discussion forums and being available to respond to concerns
 - Being open about potential interests in the outcomes of research, such as consumers' individual health, or the researcher's financial benefits from a funding source.
- This can be addressed by adequate consideration of risks and benefits for all concerned and the provision of information before the study begins.

Wider, more active participation includes consumers and researchers involved through a variety of mechanisms in setting the agenda, deciding on what questions to ask and on how results should be described and disseminated. To accomplish this, the preliminary findings of the study were presented in draft to the reference group, which represented the main stakeholders and providers of services, including consumers. The draft report was circulated 10 days before a forum held for discussion of the findings. The discussion forum acted as a validation and exploration process for the outcomes of the research and allowed us to examine data in detail.

Participants' need for expression

It was not anticipated that consumer participants would benefit directly through participation in the study, other than by being given the opportunity to express opinions, help form recommendations and to contribute to a developing body of knowledge. Several bereaved participants rang or wrote to express their support or gratitude for the project. An elderly man wrote to the Department of Health expressing his 'many thanks and congratulations,' including a 20-cent donation. Many expressed how few resources or services were available and how no support had been offered to them in their own experience. Some participants told distressing stories of their experiences. Others explained their uncertainty about how they would feel participating in the study, but subsequently found it to be their first opportunity to express their experiences, and

for it to be part of their healing process. Some had been bereaved for up to 25 years, others for as little as a month. Bereaved people from interstate wanted to participate and, being unable to do so, expressed a desire for a similar study in their own state.

We felt honoured by consumers' support and appreciation for the study, and the depth of involvement offered by some participants. On completion of the study, a greetings card was sent to all participants expressing our best wishes and gratitude for their contribution.

Bridging the divide

Reports of consumers in research recommend a greater focus upon choice to participate, consideration of the individual within the client, providing accepting, supportive environments and using professional expertise to guide the consumer towards meaningful participation.¹³ Adhering to these principles developed a sound and rewarding partnership for all.

Protected partnerships of consumers and researchers

We recognized that the project was working in a personally sensitive area for bereaved individuals. Consequently, every effort was taken to minimize the risk of causing distress in persons suffering altered thought and decision making functioning due to their grief.^{10,11} Measures taken included:

- Insisting that the researcher engaged to assist with the project had experience and demonstrated ability to deal effectively with distressed people
- Keeping the need for sensitivity and simplicity in mind when structuring the survey questions
- Designing user-friendly information fliers about the project for bereaved people
- Providing information about where participants could obtain further help in the event of distress³

What consumers contributed

Involving consumers in health-care research has the potential to inform health professionals about best practice procedures. For example, the findings indicated that a lack of training and appropriate attitudes among health providers was a major issue. Responses from participants included:

Some seemed fearful of my grief, . . . wanted to give me sleeping tablets and said 'Don't start crying I don't know how to help you'.

. . . seemed uneducated about suicide and its impact. Appeared too busy to listen; appeared to be judgemental and quick to draw inaccurate conclusion; very insensitive to family needs.

I found on several occasions that professionals who had not themselves lost a loved one through suicide, to be quite damaging to me.

Education and training that is specifically related to suicide grief service management might provide professionals with the tools to provide appropriate care and support to people bereaved through suicide.

For some participants, taking part in the study became part of their personal meaning reconstruction, whereby persons find renewed meaning in their lives through restoring their faith in themselves by assisting others or writing about their own experiences:

I am participating in this questionnaire as part of my own healing.

We also received offers of continued assistance:

I would like to be kept involved and informed of what your research identified. Should you wish to talk to me about my experience please do not hesitate to contact me. Thank you.

I hope this extra information will all help your research and if you require any more information please contact me.

I have many comments about the way my husband was treated and myself. If I can help, please call.

I am grateful for the learning and growing of the experience and thinking of it in this way has been a great help. Thank you for offering the opportunity to be involved in something like this.

On the whole, participants enjoyed taking part in the research study and valued it as an opportunity to express much about their experiences that had remained contained for some time. In itself this is an indicator for greater awareness about the health requirements and implications for those who have experienced a traumatic health event.

Limitations of the study

Because of budgetary limitations we were unable to include populations in rural and remote areas, Aboriginal and Torres Strait Islanders and schools. An attempt was

made to target people from non-English-speaking backgrounds by advertising on ethnic radio. All participants were able to read and write English.

Conclusion

The involvement of consumers in this research helped to guide the research process throughout the project, not just at the end. As a result of their involvement as participants and as members of the project reference group and the discussion forum, the final recommendations were more realistic, applicable and appropriate. Research is conducted for knowledge creation and developing a better understanding in some area. We found that consumers facilitated the transfer of specific knowledge that is needed for defined knowledge development. Involving consumers gave overt recognition of their knowledge and fostered change in the attitudes, skills and behaviour of health services researchers. Conducting participatory research made it possible to recognize shared interests among those doing the work, the people the work was designed to reach, the project funders and other stakeholders. Unfortunately, this study did not adequately investigate the needs of culturally appropriate services for people of non-English-speaking backgrounds, and indigenous peoples as well as for gay and lesbian groups and others. Further research investigating the needs of these groups, the rural and remote population, and children and young people, would be beneficial.

Research into suicide postvention with specifically nominated funds that do not become consumed by prevention research is ideal. In addition, there is a gap for nursing research to be grounded in clinical and service provision and identify acceptable models of nursing care and services to improve health outcomes and direct the formulation of better health policy. Because of their closeness to consumers, nurses are well placed to include them as clinical and research partners.

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