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Development of a Recovery Manual for Suicidal Patients with Schizophrenia: Consumer Feedback

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Abstract

A recovery-oriented manual was developed for patients with schizophrenia and suicidality. It included psychoeducational information, vignettes, “workbook” sections and was reviewed by experts in suicidology, recovery, patient education, manual development and psychosocial interventions. The revised version was tested in 22 consumers with schizophrenia and a history of suicidality. Consumer-based focus groups yielded five key themes which were used to further refine the manual. A satisfaction survey indicated that 85% stated the manual was ‘somewhat easy’, ‘easy’ or ‘very easy to read.’ All stated it was ‘very useful’, ‘useful’ or ‘somewhat useful.’ Thus, the manual appears to be acceptable and useful.

Keywords

Schizophrenia; Suicide; Manual; Prevention; Recovery; Qualitative research

Introduction

Patients with schizophrenia and other serious mental illnesses have a higher risk of premature death compared to individuals in the general population (Colton and Manderscheid 2006; Dickey et al. 2004). It has been demonstrated that clients served by public mental health centers average 8.8 more years of potential life lost compared to individuals in the general population. Most causes of death reported were natural causes and included heart disease, cancer, cerebrovascular disease and lung disease (Dembling et al. 1999). Among individuals with schizophrenia, suicide is a leading cause of premature death. Some 40–50% of people with schizophrenia report suicidal ideation at some point in their lives and 4–13% eventually commit suicide. The greatest risk for completed suicide occurs between 20 and 39 (Evenson et al. 1982; Haas 1997; Kasckow et al. 2011b). Thus, effective interventions are needed to help patients better learn to manage suicidal thinking to reduce their risk of suicide.

Treatment for suicidal patients with schizophrenia consists of pharmacologic and psychosocial interventions. There is evidence that clozapine can reduce suicide risk; however, the effects achieved with this are not marked and additional treatments are needed (Kasckow et al. 2011b).

The assessment of subjective measures of self experience is important since these measures are linked to important objective measures of health (Lysaker et al. 2006). This is especially pronounced in individuals with schizophrenia and suicidal behavior. In general, interventions focusing on subjective and personal experiences of individuals with schizophrenia have been neglected (Williams and Collins 1999). Thus, there is a need for interventions for individuals with schizophrenia and suicidality which focus on patients' experiences. Developing a patient-oriented recovery manual is one such strategy.

We developed a patient-oriented recovery manual for suicidal patients with schizophrenia. The focus of the manual was psychoeducational and incorporated cognitive—behavioral and problem solving components applicable to a population of patients with schizophrenia (Xia et al. 2011; Schooler 2006; Comtois and Linehan 2006). The purpose of this paper is to present participant feedback we obtained from our mixed-methods study design. The feedback we obtained was used to further revise the manual.

Methods

The process used to create the manual and a description of its contents has been described previously (Kasckow et al. 2011a). Once an initial draft was created, we revised the manual based on feedback from a panel of experts in suicidology, recovery, patient education, manual development and psychosocial interventions. The feasibility and acceptability of the revised manual was then tested among consumers with schizophrenia and a history of suicidal behavior. Recruitment took place at the VA Pittsburgh Health Care System Psychosis service between 9/2009 and 3/2010. Inclusion criteria, as described previously (Kasckow et al. 2011a) included (1) age ≥ 18, (2) a diagnosis of schizophrenia or schizoaffective disorder based on the Structured Clinical Interview for DSM-IV, (3) a Mini Mental Status Exam score ≥ 21 (Folstein et al. 1975) and (4) documented evidence of a history of suicidal ideation or attempt.

Patients met three times. During visit 1, demographic and clinical assessments were obtained as reported previously (Kasckow et al. 2011a). Participants then completed 2 more visits. During the first hour of each visit, participants read each half of the manual and then completed a self-report satisfaction questionnaire (see “Appendix” below). During the second half of visit 2 and 3, participants were then engaged in a focus group discussion to discuss their reactions to the manual; these lasted between 26 and 45 min. There were 2 group facilitators; the lead facilitator (CA) was a sociologist; the co-facilitator was a clinical psychologist (SH).

The focus groups were audiotaped and transcribed verbatim. A grounded theory approach drawing on the constant comparative method for qualitative data analysis was used (Glasser and Strauss 1967). Responses were compared and contrasted to develop a complete set of codes and subcodes. Each quotation was examined to determine how it fit in with the iterative thematic scheme. An overall list of concerns was developed into a qualitative codebook which reflected the reactions participants had expressed about the manual. The initial coding involved the consecutive selection of quotations for each of the main coding categories. This was later reduced to representative quotations as thematic saturation was reached. To determine the intercoder reliability, the transcripts were independently reviewed by 2 of the researchers (JK and LF) and following review, they met and discussed discrepant codes. The process continued until the analysts agreed on 100% of the coded responses.

For the Quantitative Data Analysis, continuous variables were assessed for normality and homogeneity of variance. Descriptive statistics characterized participants with means/standard deviations or percentages.

Results

Twenty-two veterans were recruited. Baseline demographic and clinical characteristics of the sample, which were obtained in the first visit, have been reported previously (Kasckow et al. 2011a). Each of the 22 veterans then participated in 1 of 4 separate focus groups during visit 2 to discuss their reactions to the first half of the manual; 18 out the 22 veterans also attended 1 of 4 separate focus groups during visit 3 to discuss their reactions to the second half of the manual. The themes and associated prominent subthemes were as follows:

Theme 1: Participants wanted to add more information.

This was the largest category with a total of 97 responses. We observed 2 subthemes which appeared frequently. The first subtheme (1a) was *Desire for more content dealing with delusions/paranoia*. This occurred 15 times and was brought up by participants in all 4 groups. As an example, when referring to the case vignettes, one participant stated: “Maybe another one might be someone suffering from delusions.”

A second subtheme (1b) was *Desire to add more on spiritual issues*. This occurred 4 times and was brought up by participants in 2 out of the 4 groups. For instance, when the group was asked what ways in the past participants had coped with suicidal thoughts, one participant stated that it would be important to include more information on spiritual issues. The participant stated “We had called upon a higher power, too. I think that would...take away the loneliness.”

Theme 2: Participants requested that changes be made to the formatting of the manual with regard to informational passages and exercises.

There was a total of 52 responses in this category. We identified 1 subtheme in this section which occurred 21 times: *Feeling too much to cover/feeling overwhelmed*. This was mentioned by participants in all 4 groups. As an example, 1 participant stated:

“There was a lot of stuff to read there and I wasn't ready to read all of it but I just filled out the questions.”

Theme 3: Participants indicated that some content may not be helpful.

There was a total of 33 responses in this category. In this section, there were 2 subthemes which were frequently observed. One subtheme (2a) we observed 9 times was *Desire to tailor the case vignettes to reflect the participants' own experience*. This was brought up by participants in 2 out of the 4 groups. As an example, one participant stated that the experiences of the individuals in the case vignettes were not representative of how he had experienced symptoms of schizophrenia; he stated: “The 2 examples [of case vignettes] were all right. They were fascinating to me but I thought, wow, those are really mellow people compared to what I was.” A second subtheme (2b) which occurred 5 times was *Desire to tailor case studies to be applicable to a wider range of reader*. This was brought up by participants in 2 out of the 4 groups. For instance, one participant recommended having one of the individuals in the case vignettes exhibit more severe symptoms. He stated: “Have 2 stories; have 1 that is more mild so that people who only have mild symptoms can relate to and then a second case...just put in 1 sample of a mild case and then Sara's case; make her the ‘John Nash’.”

Theme 4: Some of the terminology used was not understood by participants.

There were 13 responses in this category. We labeled as 1 subtheme *Problems with Vocabulary*. This occurred 10 times and was brought up by participants in 2 out of the 4 groups. As an example, in response to the facilitator's question as to whether there were any sections that were hard to understand, one participant stated: “One word is cognitive. Instead of using cognitive, you could have used thinking....”

Theme 5: Participants had a response to the content which was not originally intended by the authors.

There were 15 responses with this category and 1 subtheme. One subtheme we identified was *Discussion of family issues not helpful or even distressing*. This occurred 5 times and was brought up by participants in 3 out of the 4 groups. As an example, one participant stated: “I didn't like the part about mentioning family and family supports... Because I don't have any family that I have contact with”

Results of the Satisfaction Survey were as follows (see “Appendix” below for Survey questions). Sixty eight percent of participants reported completing the entire manual and 85% of participants found that the manual was ‘somewhat easy’, ‘easy’ or ‘very easy to read’. Forty-five percent of participants reported that the manual was ‘very useful’, 45% reported it as ‘useful’ and 10% reported it as ‘somewhat useful’. None stated that it was ‘minimally useful’ or ‘not useful at all’.

Discussion

With this study, we obtained both quantitative and qualitative feedback from consumers for a recovery manual designed for patients with schizophrenia and a history of suicidal behavior. The qualitative data described detailed comments of health consumers on how to improve the manual. We identified 5 subthemes among participants' suggestions for improving the manual. They indicated the need to: (1) add more information that participants wanted, (2) improve formatting, (3) remove portions that were apparently not helpful, (4) point out which sections lead to difficulties in understanding, and (5) be aware of unintended responses to the content. The information obtained from all 5 themes was utilized to make manual improvements. For example, in response to feedback from theme 1,

we added more content related to spiritual matters and altered the patient vignettes so that the psychopathological presentation was more representative of the participants' experiences.

With the satisfaction survey, participants reported that, overall, the manual was easy to read and the majority stated it was useful for learning new coping strategies. In addition, most of the participants stated that they were able to complete the majority of the manual in the time allotted. However, there were reports from participants in the focus groups which indicated that they felt rushed when trying to complete reading and filling out one half of the manual within an hour period. Our goals are to eventually have patients use this manual in a modular format, most likely over 6–8 sessions with the guidance of a therapist. It would have been ideal to have had participants read smaller portions of the manual over 6–8 sessions so that they could have focused on less content each time and not have felt rushed. However, this would not have been feasible given the many difficulties this population faces with regards to research participation as outpatients (e.g., transportation limitations). In order to minimize participant burden, we designed this study so that feedback could be provided over 2 visits.

Based on the Patient Outcomes Research Team study of schizophrenia, treatment for this population needs to be comprehensive, with psychosocial, rehabilitative, and family treatment programs (Lehman and Steinwachs 1998). The use of a recovery manual for suicidal patients with schizophrenia is consistent with this strategy. The development of this coping manual for suicidal people with schizophrenia is still evolving. This was the first stage of feasibility testing and at this stage we have not yet tested whether the manual affects suicidal ideation or intentions in this patient population. Once further feasibility testing trials with this manual are completed, future studies will focus on whether the manual can improve outcomes.

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Appendix: Opinion of Suicide Recovery Workbook Modules

1. How much of this Suicide Recovery Workbook module did you actually read and complete? ___ all/most of it (75–100%) ___ a good deal of it (50–75%) ___ some (25–50%) ___ little of it (less than 25%) ___ none of it
2. How easy or difficult was this Module to read or understand? ___ Very Easy ___ Somewhat easy ___ Moderately difficult ___ Very difficult
3. Overall how useful was this module? ___ Very useful ___ Somewhat useful ___ Minimally useful ___ Not useful at all

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