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How the Illness Management and Recovery Program Enhanced Recovery of Persons With Schizophrenia and Other Psychotic Disorders: A Qualitative Study

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A B S T R A C T

This study aims to describe how the Illness Management and Recovery program enhanced recovery of persons with schizophrenia and other psychotic disorders from their own perspective. Participants valued learning how to divide huge goals into attainable steps, how to recognize and prevent a relapse by managing symptoms, practicing skills, and talking openly about illness related experience. They learned from the exchange with peers and from the information in the IMR textbook. Nurses should have continuous attention and reinforcement for progress on goals, skills practice and exchange of peer information. A peer-support specialist can contribute to keep this focus.

Schizophrenia and other psychotic disorders (PD's) are characterized by the presence of delusions and hallucinations (APA, 2000) and when it lasts longer than a couple of years belongs to the category of severe mental illness (SMI) (Delespaul, 2013). Like other SMI, a PD can cause—and is due to—serious impairments in social and/or occupational functioning, and needs coordinated multidisciplinary care (Delespaul, 2013). Persons with a PD often experience failure and a sense of demoralization, which is characterized by feelings of helplessness, incompetence, diminished self-esteem, hopelessness, entrapment, aloneness and meaninglessness (Cavelti, Kvrgic, Beck, Rüsch, & Vauth, 2012). The treatment of this chronic condition is focused on clinical as well as on personal recovery (Slade, 2009). Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993).

The Illness Management and Recovery (IMR) program is a complex intervention that aims to help persons with a PD and other SMIs to develop personal skills for managing their mental illness and moving forward in their lives (Gingerich & Mueser, 2011). The program includes five evidence based methods: psycho-education, cognitive–behavioral approaches to medication adherence, relapse prevention, social skills training and coping skills training (Gingerich & Mueser, 2011; Mueser et al., 2006). The IMR program is developed as a standardized curriculum-based program containing 11 modules concerning clinical and personal recovery (Box 1.).

The IMR program, which is tailored to individual needs, requires approximately nine months, when delivered in weekly sessions. Each session follows a uniform structure facilitating education of illness management skills and making progress toward recovery goals. The program is provided by IMR certified professionals and peer-support specialists (Garber-Epstein, Zisman-Ilani, Levine, & Roe, 2013).

In randomized controlled trials (RCT) (Färdig, Lewander, Melin, Folke, & Fredriksson, 2011; Hasson-Ohayon, Roe, & Kravetz, 2007; Levitt et al., 2009) and in quasi-experimental trials (Fujita et al., 2010; Garber-

Abbreviations: IMR, Illness Management and Recovery; SMI, Severe Mental Illness; PD, Schizophrenia and other Psychotic Disorder.

We confirm that all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

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Box 1
IMR Modules

1. Recovery Strategies
2. Practical Facts about Mental Illnesses
3. The Stress-Vulnerability Model
4. Building Social Support
5. Using Medication Effectively
6. Drugs and Alcohol Use
7. Reducing Relapses
8. Coping with Stress
9. Coping with Persistent Symptoms
10. Getting Your Needs Met in the Mental Health System
11. Healthy Lifestyles

Epstein et al., 2013; Salyers, Rollins, Clendenning, McGuire, & Kim, 2011; Salyers et al., 2010) the IMR program has shown significant improvements in illness management, psychosocial functioning, knowledge about the illness and goal-setting skills (Hasson-Ohayon et al., 2007). Next to the effectiveness of the IMR program, one wants to understand how this complex intervention enhances the recovery of persons with an SMI in order to reinforce this focus. Recently McGuire et al. (2014) investigated critical elements of the IMR program from the perspective of sixty-seven experts who rated 16 IMR elements. But, the call for qualitative analysis of complex interventions is growing, which allows in-depth exploration of the pathway of change and active ingredients which are too complex to be captured quantitatively (Craig & Petticrew, 2013). Only one study of the IMR program obtained qualitative data (Roe, Hasson-Ohayon, Salyers, & Kravetz, 2009) which identified attributed improvements and the uniqueness of the IMR program. However, so far there is no study that provides insights about the active ingredients within the IMR program from the viewpoint of people with an SMI themselves and how the program exerts its effects. Because of our sample of persons with a PD, the aim of our study was to gain insights into the IMR program's ingredients that enhanced recovery from the perspective of persons with a PD, who completed the IMR.

1. METHODS

1.1. Design

A descriptive phenomenological design was used to explore personal retrospection on experiences with the IMR program. Phenomenological inquiry is an approach that can be used to examine and recognize the lived experience that is commonly taken for granted (Bouije, 't Hart, & Hox, 2009). The personal experiences were registered in one-to-one interviews with persons who attended the IMR program in the past.

1.2. Participants

Participants were recruited in one outpatient unit for persons with a PD in the Netherlands. All participants took part in one of three separate IMR-program groups that finished one, 13 or 19 months before the interview. Two certified IMR trainers, a mental health nurse and a peer-support specialist, provided the IMR groups. This outpatient clinic was audited in 2011 and evaluated with an excellent implementation score on the IMR Fidelity Scale and General Organization Index (Saxion, 2011).

Persons were included in the study when they met the criteria: having schizophrenia or another psychotic disorder (APA, 2000), a period of two years since onset of the illness before they started the IMR program, and having completed the IMR program. We defined completers as having an attendance rate of at least 70%, as a 100% is not realistic in a weekly IMR-program group, which took approximately nine months. Persons with a lower attendance rate might have missed too many sessions and ingredients of the IMR program. After missing a session, participants received individual attention of a trainer to be able to catch up with the group again. Persons who experienced difficulties in communication due to substance use or psychotic experiences at the time of the interview were excluded from the study.

From the list of persons who attended the three separate IMR-program groups, the IMR trainers identified 14 potential participants meeting the in/exclusion criteria. These potential participants were asked to participate by their mental health nurse and received oral and written information about the study. The researcher phoned these persons to provide further information and made an appointment for the interview. A total of eight persons were willing to participate in this study.

1.3. Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki. After consulting the Dutch Central Committee on Research Involving Human Subjects, we concluded that ethical approval was not obliged because participants did not receive treatment, nor were they asked to behave in a particular way (CCMO, 2016). Approval for this study was obtained from the Board of Directors of the mental health organization involved in this study. Before starting the interview participants signed an informed consent.

1.4. Data Collection

Open interviews were executed in the period of September 2013–January 2014, with an average duration of one hour. Each interview was guided by a topic list, which was used as an Aide Mémoire, to guide the participants back when distracted from the main subject: the IMR program. The topic list was developed after reviewing recovery literature, a pilot interview and discussions within the research group. Two open questions were asked in each interview: "You have participated in an IMR programme; how did you experience this programme?" and "What does recovery mean to you?" Together with the participants, the interviewer took special attention to investigate whether or not experiences were the results of the IMR program. After the data analysis of the first three interviews, the topic list was modified in consequence of the first results. The interviews took place at the locations of the participants' preferences where they felt at ease; at home or in the outpatient unit. The interviewer ensured that the interview was not disturbed by a telephone call or another one's presence.

All interviews were voice recorded and transcribed verbatim. At the end of each interview the findings were summarized and checked with the participant to ensure that the accuracy of the experience was grasped.

1.5. Data Analysis

In this study, the Colaizzi's data analysis method was used as described by Holloway and Wheeler (Holloway & Wheeler, 2006) and supported by the MAXQDA® computer software. The first step, following Colaizzi's method, started with a thorough reading and re-reading of the transcripts in order to obtain a general idea about the whole content. The second step was the extraction of significant statements of each interview. The researcher (first author), the peer researcher (LvdM), and the supervising researcher (second author) coded the first three interviews independently and discussed their differences until consensus about the coded text was reached. The two researchers independently coded three more interviews.

After analyzing the sixth interviews, data saturation seemed to be achieved, which was confirmed in the two last interviews. Statements were formulated in significant codes, sorted into categories and clustered into themes. Different opinions were discussed with all researchers to

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