Connecting visions and voices: Involving service users in realizing 'good mental health care'

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2013

document version
Publisher's PDF, also known as Version of record

citation for published version (APA)
van der Ham, A. J. (2013). *Connecting visions and voices: Involving service users in realizing 'good mental health care'*. Gildeprint.

CHAPTER 5

The implementation of Psychiatric Advance Directives: experiences from a Dutch crisis card initiative

Abstract

The crisis card is a specific form of a psychiatric advance directive, documenting service users' treatment preferences in advance of a potential psychiatric crisis. In this paper we aim to provide insight in implementation issues surrounding the crisis card. A Dutch crisis card project formed the scope of this study. Data were collected through interviews with fifteen participants from six stakeholder groups. Identified implementation issues are: 1) the role of the crisis card counsellor, 2) lack of distribution and familiarity, 3) mental health care professionals' routines, and 4) service user readiness. The crisis card counsellor appears to play a key role in fostering benefits of the crisis card by supporting service users' perspectives. More structural integration of the crisis card in care processes may enhance the impact of the crisis card, but should be carefully explored.

Introduction

Over the last decade several types of Psychiatric Advance Directives (PADs) have been developed to document service users' treatment preferences in advance of a potential psychiatric crisis in which the individual is unable to communicate his wishes (Atkinson et al., 2003). Proposed benefits of PADs include improvements in crisis care, enhancing service user involvement in care and promoting service user autonomy (Srebnik, 2004). However, the usefulness of PADs may be hindered by practical issues of implementation, reservations and resistance among health care providers, ambiguity about the legal status of such documents and barriers for service users to complete PADs (Atkinson et al., 2004; Backlar et al., 2001; van Dorn et al., 2006; Kim et al., 2007).

The 'crisis card' is a specific type of PAD which finds it origin in the consumer movement in the UK (Sutherby & Szmukler, 1998). It is a small document - the size of a bank card - containing practical information about preferences for future crisis care and a contact person nominated by the user. Although benefits and barriers for crisis cards may be similar to those of PADs, literature on this topic is scarce, especially considering implementation issues. In this paper we aim to add to the existing literature by providing insight in implementation issues surrounding the crisis card. We draw upon the experiences of various stakeholders with the implementation of a crisis card in the Netherlands. Findings may help to strengthen existing crisis card projects and contribute to the development of new crisis card initiatives.

Methodology

In the Netherlands, the crisis card was introduced in 1999 by an advocacy group for people with mental illnesses, which holds copyright over the concept of the crisis card. This copyright which is only given to cards developed from the service users' perspective with the help of an independent crisis card counsellor. In 2011 there were thirteen crisis card initiatives. The mental health care provider in this study started using the crisis card in 2008 and by 2011, 90 service users had a crisis card. These crisis cards were produced with the help of two crisis card counsellors who themselves had previously experienced psychiatric crises.

Data were collected through in-depth interviews with fifteen participants from six stakeholder groups: health care professionals (5), a manager of the mental health provider (1), service users (4), a family member (1), crisis card counsellors (2), police officers (1) and a general practitioner (1). Interviewees were recruited through the network of the crisis card counsellors using purposive sampling methods; we aimed for diversity in

stakeholders and experiences. Service users were all in the possession of a crisis card and other stakeholders were familiar with the crisis card.

The semi-structured interviews included topics about perceived benefits of the crisis care and implementation issues. Interviews were – after obtaining informed consent – audio-recorded and transcribed verbatim. A summary of the content was sent to the interviewee for verification. Transcripts of the Interviews were coded manually. Commonalities in participants' responses were identified, coded and merged into broader categories.

Results

Four categories of implementation issues emerged from our analysis: 1) role of the crisis card counsellor, 2) distribution and familiarity, 2) care professionals' routines, and 3) service user readiness.

Role of the crisis card counsellor

According to service users and crisis card counsellors the assistance of a crisis card counsellor is very important in their decision and process of developing a crisis card. Service users indicated that it is easier to explain themselves to someone who knows by experience what they are going through. The value of the crisis card counsellor was also stressed by the manager from the health care institution:

> *I think the success of the crisis card is mainly due to the enthusiasm of the crisis card counsellor who is able to explain the importance of developing and having a crisis card for service users. This kind of missionary work is the role of the crisis card counsellor.*

Lack of distribution and familiarity

The interviewees indicated that many people outside the institution are unaware of the fact that service users can carry a crisis card with them and as a consequence they rarely ask or search for it in the event of a crisis. People who do encounter the crisis card in a crisis situation, often see the card for the first time and do not immediately understand the purpose. A service user said:

> *It would be nice if more people were familiar with the crisis card. Then, they wouldn't react in such a strange way if they see it.*

Several care providers and a police officer mentioned the lack of structural integration of the crisis card in care processes as an obstacle to its distribution and implementation. They suggested that mental institutions should make the development of the crisis card a standard part of care. In addition, the police representative suggested making the crisis

card electronically available to the police to improve collaboration and communication between care providers and police.

Care professionals' routines

Although most care professionals are familiar with the card, they often do not inform service users about it. According to interviewees this is because it is not part of their routine; they forget to consider the crisis card. Moreover, they have little time for this in their busy daily schedule. Several care professionals indicated that some of their colleagues were sceptical toward the crisis card and doubted its benefits. One of the care providers said:

> *It's not a conscious decision; maybe it's my shortcoming that it doesn't come to my mind. . Maybe it's also partly because I don't know the effect. If I knew the effect I would be more enthusiastic.*

Service user readiness

Several care professionals raised questions about the number of service users showing enough self-insight to use the crisis card adequately; they suspected that few service users would be capable of doing this. However, a crisis card counsellor emphasized that insight does not form a prerequisite for developing a crisis card; a service user's motivation is more important. Several service users indicated that it can be very confronting to develop a crisis card because it reminds them of experiences they prefer to forget. Service users might also feel that having a crisis card labels them as 'mad' and feel shame for being ill, as illustrated by a service user's comment:

> *There were moments that I chose not to hand over the crisis card to someone. I was ashamed; ashamed for the fact that I am ill.*

Discussion

This study describe a promising initiative in which a mental health care provider successfully adopted a service user and consumer-movement based type of a psychiatric advance directive; the crisis card. The crisis card counsellor appears to play a key role in this collaboration by working within the context of a mental health care provider and at the same time promoting and protecting service users' perspectives and interests.

Despite the proposed benefits of the crisis card, participants from all stakeholder groups recognized the lack of distribution and limited implementation as an important concern. Studies about PADs similarly identified barriers to implementation (Backlar et al., 2001; Kim et al., 2007). In our study, limited implementation may be partly related to the decentralized character of crisis card initiatives in the Netherlands; implementation

depends on regional initiatives, often from service user interest groups with limited resources. Furthermore, successful implementation depends on collaboration with professionals and endorsement of the crisis card by professionals can form a barrier. Scepticism toward service user-based interventions may also play a role, considering that professionals questioned service users' abilities for developing and using the crisis card. In addition, professionals may differ in the extent to which they are willing to follow the service user's preferences when it opposes their own view in a crisis situation (Atkinson et al., 2004; van Dorn et al., 2006; Elbogen, 2006).

Care providers in our study suggested more structural integration of the crisis card in the treatment process to increase distribution of and familiarity. However, if the crisis card would become a standard part of care provided by the institution, it might become more the decision of the health care provider than the service user's choice to develop the crisis card. This possibly compromises the service user-based principles of this instrument. Opportunities for more structural integration of the crisis card in care processes should therefore be carefully explored.

Generalization of the findings is limited because of the small number of respondents per stakeholder group and the specific characteristics of the setting in which the study took place. However, the findings in our study are largely in line with literature and participants' responses were largely overlapping. The study thereby provides useful starting points for further research the crisis card and its contribution to personal and clinical recovery.