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van der Ham, A.J.

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CHAPTER 4

Experiences and effects of the crisis card: an evaluation study

Abstract

The crisis card is a tool to help people with psychiatric problems to determine how they want to be treated in a crisis situation. In order to gain better insights into the experiences of diverse stakeholders with the crisis card, an evaluation study was undertaken within a mental health care institution which used the crisis card. Research shows that experiences with the crisis card are positive. A number of effects were identified, the strongest of which are the psychosocial effects.

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Introduction

A crisis card is a small personal document that gives users of mental health services the opportunity to arrange in advance the process to be followed in the event of a psychiatric crisis. The card describes what the service user's psychiatric crisis looks like and what should happen in this eventuality taking into account the service user's treatment preferences. In times of severe confusion or anxiety, the crisis card provides passersby, relatives and care providers with instructions on how to act.

The service user determines him or herself what is on the crisis card. This is done when the service user is stable and when he or she has clearly decided what is and what is not appropriate in the event of a crisis. The service user is supported by a dedicated counsellor who is independent of healthcare institutions. The adviser works for a service user advocacy organisation and is often an expert counsellor who has personally experienced psychiatric crises. The crisis card counsellor helps the service user in the preparation of a comprehensive crisis card plan. When all involved health care providers, contact persons and the service user agree on the plan, they sign it. The crisis card represents a summary of this larger crisis plan.

The concept of the crisis card comes from the service user advocacy movement and was developed to help service users protect their own interests (Sutherby & Szmukler, 1998). In the literature, the crisis card is referred as a form of an *advance statement*. In such statements, service users give their intention in advance about preferences for care (Henderson et al, 2008). These statements give service users more control over decisions about their treatment in crisis, reducing compulsion and pressure (Atkinson et al, 2003). In the literature, the crisis card is also seen as a form of an *advance agreement* in which agreements about any future crisis situation are made in advance by the service users, care providers and others who are directly involved (Ruchlewska et al, 2009). In addition, the crisis card is sometimes also referred to as an *advance directive*. Psychiatric Advance Directives (PADs) are legal documents that 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).

The Dutch crisis card plan is part of the treatment contract as described in the Law on Medical Treatment Agreement (*Wet op de Geneeskundige Behandeloovereenkomst* WBGO) and is also a declaration of intent. Negative intentions (things that someone does not want) should be respected according to the WGBO unless there are good reasons for deviating from them as, for example, in the case of compulsory admission. Positive intentions (things that someone wants) are not legally enforceable.

In the UK, the first crisis card was introduced in 1989 (Sutherby & Szmukler, 1998). In 1998, the Amsterdam Patients and Consumers Platform (APCP, now merged into

Clientenbelang Amsterdam) used this example to develop their own crisis card. Since then, interest in the crisis card has slowly grown. Most initiatives come from regional service user organizations, although some healthcare institutions also offer the crisis card. The neutrality of the crisis card is protected by a copyright belonging to the APCP. This copyright serves as a guarantee that the card has been developed from a service user perspective.

Effects of the crisis card: need for research

Although the crisis card has been in existence for over twenty years, there is little scientific literature on its effects (Henderson et al, 2008; Ruchlewska et al, 2009). There are a number of studies on other forms of advanced statements (Henderson et al, 2004; Srebnik et al, 2005; Papageorgiou et al, 2002), although the results are mixed. There seems to be only one study that focuses specifically on the crisis card (Sutherby et al, 1999), involving a study of 42 service users in the UK. The study shows that the crisis card was able to provide information to health care providers and passersby in situations when the service user is no longer able to do this. In addition, the crisis card was found to have a positive impact on the psychological functioning and quality of life, improving, for example, the service user's confidence, insight in their illness and relationship with health care providers.

In the Netherlands, some positive experiences with the crisis card have been recorded (Basisberaad Rijnmond, 2004). To better understand the experiences and effects of the crisis card in the Dutch context, more research is required. For this reason, we performed an evaluation of the use of the crisis card by a mental health care institution in the province of Gelderland. The institution has used the crisis card since 2008. In early 2011, almost ninety of their service users had a crisis card. Our study had three goals. First, describing the effects of the crisis card from the perspective of the different stakeholders. Second, investigating the experiences of those using the crisis card. Third, identifying bottlenecks in the preparation and use of the crisis card.

Use of the crisis card: research approach

In 2011, ten semi-structured interviews were conducted with a total of fifteen stakeholders. Some interviews included several people. The interviewees comprise: six health care professionals working at the mental health care institution (three out-patient care providers, two in-patient care providers, a team leader), four service users, two crisis card counsellors, a partner of a service user, a representative of the police and a representative of the general practitioners' emergency post² for out of hours care. All

² huisartsenpost

interviewees were identified through the informal network of the third author, a crisis card counsellor. The service users interviewed were all in possession of a crisis card. The other participants were all familiar with the crisis card. Experience of using the crisis card was not a prerequisite for participation in the interviews. Interviewees were selected to include a diversity of experiences with the crisis card.

The interviews were conducted by a researcher from the VU Medical Centre, Amsterdam, on the basis of a predefined topic list. The interviews lasted half an hour to an hour and took place in the building of the mental health care institution or at a location preferred by the interviewee. A verbatim transcript was made of all interviews. A summary of the transcript was sent to the interviewees for verification. The interview data were analyzed on the basis of the main issues: effects, use, and bottlenecks and suggestions.

Effects of the crisis card

After analysis of the interviews, we were able to divide the effects of the crisis card into three categories: psychosocial effects, effects on the crisis situation, and effects on hospital admissions. Each category includes several themes (see Table 4.1).

Table 4.1. Categories of crisis card effects and related themes

Categories	Themes
Psychosocial effects	Understanding / Insight
	Security / Safety
	Empowerment/Autonomy
Effects on crisis situations	Acting efficiently
	Approach service users in the right way
	Prevent escalation
Effects on hospital admission	Reduce admissions
	Service user-centered care

Psychosocial effects

All interviewees mentioned the psychosocial effects of the crisis card and the majority of them found these to represent the clearest effects of the crisis card.

First, the crisis card appears to improve all stakeholders' **understanding and insights** into the crisis. Through the process of drawing up and discussing the crisis card, the service users develop insights into their own crisis, what it looks like, what the early signs are and the actions that passersby should take. The crisis card also helps family and friends in the

same way. Service users told that they were using the crisis card as the basis of discussions with their families and friends. As a result, families and friends came to know more about how a crisis arises and the signs of a crisis, and they were also able to express their understanding. Information on the crisis card also helped health care providers to develop more insights into the crises of people with mental illnesses. The crisis card was able to offer them new insights because it provides information from the perspective of the service user, often different to the perspective of health care providers.

Second, the crisis card was found to have a positive effect on feelings of **security and safety** for different stakeholders. Due to the crisis card, service users know what will happen if a crisis occurs and they feel that it protects them. One of the interviewed service users said: *Because I now have it [the crisis card], I'm more confident being away from home.* For close family and friends, the crisis card also provides security and peace of mind. They find it comforting to know that if the service user experiences a crisis when they are not there, others can read what is going on and what needs to happen. A close relative said:

[The crisis card] also gives, you know, some peace of mind [...] From the outside, you can't see what's wrong with her but the crisis card will let people just know, okay fine, that is going on. And then you can make a quicker diagnosis, I think.

Although care providers have limited experience with the crisis card to date, they also think that it can give more security and clarity in crisis situations. Health care professionals providing outpatient care at the mental health care institution also found it reassuring to know that they would be contacted if any of their service users was experiencing a crisis.

Third, it appeared that the crisis card reinforced the **empowerment and autonomy** of service users. Service users can discover and record their own wishes and preferences. This gives them more control over what happens to them in situations when they cannot make these wishes and preferences known. One of the interviewed service users summarized this as follows: *If I am not able to talk, the talking will be done for me.* In addition, health care providers prefer that service users are able to exercise more control and autonomy because it increases their self-reliance. The crisis card also appears to strengthen the role of the family members because it gives them a clear place in the care process. The crisis card counsellors also mentioned that they themselves feel empowered by the developments they go through in their role as counsellor in this institutional setting.

Effects on crisis situations

The interviews demonstrated that the crisis card had three important effects on the course of crisis situations. First, the crisis card helped passersby to **act efficiently** in crisis situations. When they consult the card, they can recognize the crisis on the basis of the description on the card. They also read what they need to do and who needs to be contacted. This makes it possible to take the right actions immediately. Service users also mentioned this as an important effect on crisis situations:

At the moment that I'm, for example, panicking in a shop and I'm with someone, they will also know what is going on and that we have to go outside, and then it will be okay.

The crisis card also helps passersby to **approach service users in the right way**. From the card, they will know how best to approach the person to calm him or her down and how to lead the situation in the right direction. They will also know which approach will have a detrimental effect on the person, or is otherwise undesirable. A service user explained how this helped her: "Then they understand better that they should not surround me with ten men." One health care provider said the following about efficient actions and how to treat the person experiencing a crisis:

I think it is important that all the information is there that you need, very concise and clear, in the event of a crisis. Including the signs, symptoms and, for example, what the person doesn't want in a crisis, like that you shouldn't touch them or that you need to talk quietly. That kind of thing, so also your attitude. Covering all things that you can do wrong, really just because you do not know someone.

Finally, the crisis card helps to **prevent escalation** of the situation. The correct actions in a crisis can help prevent the person experiencing a crisis from becoming even more in a crisis and worsening of the situation. Treatment can also be started at an earlier stage of the crisis, making the course more favourable. This is reflected in the following comment from a counsellor:

I do not think you can always prevent a crisis but you can resolve the crisis sooner. You can intervene earlier which can help avoid complications.

Effects on hospital admission

In addition to the psychosocial effects and effects on the crisis, the interviewees reported effects on the admissions in the event of a crisis. First, according to many of the interviewees, the crisis card helps to **reduce the number and duration of admissions**. Given that interventions can be started at an earlier stage and there is less chance that the crisis escalates, some interviewees think that the crisis card can also prevent that someone has to be admitted at all. However, they could give no concrete examples of this happening. In the event that admission is needed, the instructions on the crisis card can help to reduce the length of admittance.

Before when I did not feel well, I would go more quickly to a TOR-bed [Time Out Scheme bed] than I did when I did not have that thing [crisis card]. Now I have got it, I'm less likely to go than when I didn't have it.

Second, according to a number of interviewees, the crisis card makes it easier to **take the wishes of the service user into account** during admission and provide service user-centred care. This might include such things as the location of the admission, arranging

practical issues surrounding the admission (for example, taking care of pets or post) and the method of treatment by health personnel.

Implementation of the crisis card

The interviews also involved questions about how the crisis card was introduced. This highlighted a number of issues: the preparation of the crisis card; the role of the counsellor; the use of the crisis card in crisis situations; and bottlenecks and areas for improvement. The results of the interviews are reviewed for each of these issues.

Preparation of the crisis plan and card

Most service users that decided to have a crisis plan and card have usually been advised to do so by health care providers. Service users usually themselves then make an appointment with the crisis card counsellor although sometimes the first appointment is made by a health care provider. In some cases, service users spontaneously make contact with the crisis card counsellor, for example if they know the counsellor or if they have read a leaflet about the crisis card.

The number of appointments that are needed to draw up a crisis card differs per person. It usually takes the interviewed service users one to six appointments with the counsellor. One of the counsellors said that some persons need more time to prepare the crisis plan because they still want to adjust many things during the process.

Service users generally found drawing up the crisis card to be a positive experience, although it also had more tricky moments. They said that they also found it confrontational and that it was sometimes difficult to answer very personal questions.

The counsellors said that drawing up the crisis card is sometimes difficult because of the need to balance the wishes of service users with what is realistic. They said that it is important to be clear about what is possible and what is not. As one counsellor put it:

It's not about what we want or what the health care provider wants on the card, it comes down to the wishes of the service user, and it is sometimes important to compromise because passersby also need to be able to understand it.

The role of the crisis card counsellor

It is clear that the counsellor plays an important role in developing the card. Important aspects are the personal experience of the counsellor, the relationship with the service user and the counsellor's position within a healthcare organisation.

The personal experience of the counsellor was seen as very important by service users. The counsellors have also experienced crises, which made the service users feel that they have

less need to explain many things. Some health care providers indicated that they find the personal experience of the counsellor to be important because they themselves cannot fully understand what people go through in a crisis.

The interviewees consider that the relationship between the counsellor and the service user is important to the success of the crisis card. Counsellors with their own personal experience have a different relationship with the service user than a health care provider. They mainly have a supportive role and can take the interests of the person with a mental illness as their perspective. As one health care provider noted:

[The crisis card counsellor] is someone who brings things from their own experience, and that can be very supportive and just a lot less threatening than someone who is in another hierarchical role than you.

The position of the counsellor in the healthcare organisations was important during the drawing up of the crisis card, according to some interviewees. A team leader told that the counsellor is part of the treatment team and therefore embedded in the organisation. Moreover, given that the counsellor has personal experience, indicates that personal experience in general receives a clearer place in the organisation. Counsellors also found this to be a positive development. According to them, the fact that the counsellor is part of the treatment team illustrates the value given to the crisis card and that the role of counsellor is also valued.

Using the crisis card

‘Using the crisis card’ refers to the experience with the use of the crisis card in concrete situations, both from the perspective of service users, crisis card counsellors, care providers (employees of the mental health institution, and representatives of the general practitioners’ post in the hospital and the police). Below, the results are described separately for the various stakeholders.

The four interviewed service users had the crisis card between eight months and three years. Three of the four service users had used the card in a crisis situation. One of them had used the card several times, but could not remember exactly how often. The crisis card had been used in different situations. One of the service users had used the card in an amusement park where he had become unwell. On his direction, his partner gave the crisis card to employees of the park and, on the basis of instructions on the card, he was offered help. The partner of a second service user had used the crisis card at home. When the first signs of psychosis appeared, her partner grabbed the crisis card and used it to guide actions. The third service user had often used the card. Once she was walking on the street and had a blackout, not knowing where she was. She gave the card to a passerby who helped. Another time she panicked at the supermarket and gave the crisis card to an employee of the supermarket who stayed with her until she felt better and could go home.

The two counsellors interviewed indicated that the crisis card was used regularly. One of them had undertaken twenty evaluations of the crisis card with individual service users during 2009-2010, showing that seven of them had used the card in crisis situations. Of the remaining service users with a crisis card, the counsellors often did not know whether they had used the card.

None of the health care providers of the mental health institution had ever known that the crisis card was used. The representative of the general practitioners' emergency post also did not know, after asking at the post, any cases where the crisis card had been used. The representative of the police estimated that the crisis card had only been used twice in a crisis situation in which the police had been involved. The interviewees think this has to do with the limited number of people with a mental illness that has a crisis card. They also consider that, in a crisis situation, no-one looks for or asks for a crisis card.

Bottlenecks and suggestions for improvement

Although all interviewees were in favour of the crisis card, a number of them also considered that there is still some room for improvement. The main topics identified in this regard were the limited awareness of the crisis card, the working routines of health care providers, and the way in which the crisis card is integrated into care. Other relevant issues relate to the target audience, the stigma of mental illness and suggestions for the content of the crisis card.

The limited awareness of the crisis card has been considered by many people as a flaw. Given that few people with a mental illness have a crisis card, many people do not know that someone in crisis may have a crisis card with them. This means that no-one asks about a crisis card or looks for one in a crisis situation. Many people who come across a crisis card in a crisis situation, see the card for the first time and sometimes initially do not know what is intended. A service user formulated this as follows:

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.

Another obstacle is the working routines of some health care providers. While many health care providers are familiar with the crisis card, they do not always inform service users of its existence. According to most interviewees, this is mainly because the crisis card does not occur to them. It is not part of their routine and they have no opportunity to consider this alongside their other daily practices. Also some interviewed health care providers thought that other health care providers are sceptical about the crisis card and have doubts about its value. One of the health care providers interviewed acknowledged this:

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.

According to several interviewees, it is unfortunate that the crisis card is not included structurally in care. A few health care providers thought it would be good to include the crisis card in the care provided by care institutions. A representative of the police considers that every person with a mental illness should have a crisis card and that it should be available electronically for all care providers. This would have a positive influence on the exchange of information and cooperation.

During the interviews, the target group of the crisis card was addressed. Some health care providers wondered how many people with a mental illness have sufficient understanding and acceptance of their disease to be able to use the crisis card adequately. They suspected that only a few of them have such insight. However, one crisis card counsellor indicated that understanding and acceptance are no conditions for making and using the crisis card. Most importantly, according to this counsellor, is that the person with a mental illness should want the crisis card themselves. The representative of the police wondered which types of people with mental illness have a crisis card and whether this is actually the same type of person that comes into contact with the police.

Some interviewees mentioned that the stigma of mental illness can be a reason for people with a mental illness not to want to make use of the crisis card. This is evident in the comment of a service user:

I've also had times when I have not given the card. I was ashamed. Then you're embarrassed about the fact that you're sick.

For some service users, the crisis card has a negative connotation because it reminds them of their crisis, which for them is a very unpleasant experience about which they do not want to be reminded. Interviewed service users suggested that other people with a mental illness could be opposed to the crisis card because it gives them the feeling that they will be labelled as 'mad'. Still others might be suspicious about the need for personal data on the card or want to hide from the outside world that they are crisis-prone.

All service users interviewed were satisfied with the content and design of the crisis card. However, they had suggestions for improvement. The partner of a service user noted that keeping the information on medication on the card up to date is very important and believes that it should be continually adjusted, for example with a sticker system. He also liked the idea that people can be directly connected with the institution by the crisis card with, for example, a dossier number.

Discussion

Our research gives an impression of the experience and effects of the crisis card. The crisis card has multiple effects which can be divided into psychosocial effects, effects on crisis situations, and effects on hospital admissions. These results are consistent with the findings

of Sutherby and colleagues (1999). The psychosocial effects described by us are very similar to the effects mentioned by them on psychological functioning and quality of life. The effects mentioned by us on crises situations and hospital admissions are similar to the practical effects described by Sutherby and colleagues.

In our study, the psychosocial effects seemed to be the strongest. In particular, the peace of mind and security provided by the crisis card were generally recognized. These are possibly the most important effect of the crisis card. However, there is still little known about the actual use of the crisis card as a result of which its effects on crises and crisis admissions may not have been sufficiently considered in our study. This lack of insight has to do with the difficulty of predicting and monitoring crises situations and the absence of a registration system.

It is interesting that the crisis card can provide a dilemma for people with a mental illness. Although service users can see the benefits of the crisis card, they do not always want to be confronted with the negative aspects of a crisis. Shame also plays a role in this dilemma. This indicates that the suitability of the crisis card varies by person and situation. At the same time, it emphasizes the importance of the initiative of the service user in the preparation and use of the crisis card. If the service user can decide whether and when to use the card, he or she can consider the pros and cons. The crisis card counsellor can help to bring the crisis card to the attention of service users and provide clarity about expectation and possibilities.

Several interviewees saw the structural inclusion of the crisis card in the care system and / or electronic records as a way to increase its effectiveness. The scope and familiarity of the crisis card can be improved by this, although a number of issues need to be taken into account. First, mental health care institutions cannot simply include the crisis card into their care. As a result of the copyright, they must first meet the criteria of the ACPC before they can use the card. Second, the crisis card is based on the needs of people with mental illnesses. When the crisis card is a structural part of care, this could be at the cost of the freedom of choice of service users, while this freedom of choice plays an important role in the success of the crisis card. In sum, while expanding the use of the crisis card can improve effectiveness, the possibilities should be carefully explored in consultation with service users, families, health care providers, crisis card counsellors, police and other relevant parties.

When interpreting the findings, we have a few words of caution. This is a small-scale study in which different types of stakeholders were interviewed. We do not know to what extent the results are representative of all those involved in the mental health care institution and other care institutions. In addition, we have no insights into the quantitative effects of the crisis card.

