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A study of 'crisis cards' in a community psychiatric service

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Objective: 'Crisis cards' state patients' treatment details and preferences in anticipation of a later occasion when the patient might be too ill to express them directly. We assessed the feasibility of introducing 'crisis cards', or a collaborative form of them, 'joint crisis plans', into a sectorized community psychiatric service.
Method: All patients with a psychosis and at high risk of crisis were invited to participate. Follow-up examined patients' satisfaction and how the cards were used.
Results: In total, 106 eligible patients were identified and offered a card, and 40% agreed to participate. Patients with an affective psychosis, past suicide attempts and less frequent admissions were over-represented among those who agreed to take part. Patients chose to include a wide range of information. For participants, admissions fell by 30% in the follow-up year.
Conclusion: Crisis cards serve both a 'manifest', practical function (to provide important information when the patient is too ill to do so) and a 'latent' psychological one (positive effects on the patient's attitude to self, their illness and treatment, and their relationship with the clinical team).

Key words: psychotic disorders; psychosocial; psychology; advocacy; community psychiatry

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Introduction

The first 'crisis card' used in the UK was developed by the International Self-Advocacy Alliance and jointly launched with Survivors Speak Out in 1989. This is the prototype for most other crisis cards currently in circulation (1, 2). It was originally intended as an advocacy device for use in mental health emergencies, allowing a service user to nominate a friend or relative to be contacted in a crisis for support or advocacy. The user may also supply any other information they wish, and request specific actions to be carried out in a crisis. It is not known how many users of mental health services currently carry a crisis card, and to date the only published report of their use has been anecdotal (3).

In England, the parliamentary Health Committee's Fifth Report to the House of Commons on Community Supervision Orders (4) included evidence given by Survivors Speak Out on the use of crisis cards or 'treatment contracts' as an alternative to compulsory treatment orders in the community. Survivors Speak Out described how a user, 'when in a rational state of mind, can set out in writing (on a crisis card) how they would like to be treated in circumstances when they are not the best judge of their own interests'. They also supported the notion of treatment contracts where users negotiate packages of care with their psychiatrist for use on future occasions when they are incapable of making a decision. The Government's response was to encourage the informal use of crisis cards and the development of practice guidance on their use, bearing in mind the central role of the user. They recommended that ways of amending the law to make crisis cards legally effective should be examined (5).

We here report a pilot study designed to examine the feasibility of introducing crisis cards or joint crisis plans within a community psychiatric service. In this paper we set down the following definitions. A 'crisis card' records a set of statements made by a patient *independently* of any agreement with the treatment provider about what should happen in a crisis. What we refer to as a 'joint crisis plan' is a similar set of statements made *in collaboration with*, and agreed with, the treatment provider. We use the term 'card' generically to refer to either of the above.

Material and methods

Subjects

The Camberwell sector of the Maudsley Hospital in South London has a population of 46 000 and is one of the most deprived areas in the UK. We aimed to offer a crisis card or joint crisis plan to all patients resident in the Camberwell sector who met the following criteria: (i) two or more admissions to hospital; (ii) at least one admission in the 2 years prior to the study's commencement; and (iii) a clinical diagnosis of schizophrenia (ICD: F20), schizoaffective disorder (F25), bipolar affective disorder (F31), depressive disorder with psychotic symptoms (F32.3 or 33.3), acute and transient psychotic disorders (F23), psychotic types of manic episode (F30.2), persistent delusional disorders (F22) or other non-organic psychotic disorders (F28). Users who fulfilled these criteria were identified, and sociodemographic and clinical data were collected from case-notes. Eligible patients were sent an initial letter offering assistance with a card, but because of the novelty of crisis cards, where possible one of the researchers or the keyworker aimed to explain their nature personally.

Design of the cards

Following consultation with national and local user groups who had tried a form of card (2), a 'menu' of possible headings for information to be included on a card was compiled. Other headings, including early signs of relapse (6, 7), were added by us, together with space for any additional items which the user might wish to include. Patients were provided with this 'menu' to help them to select what they wanted on their card. They could include as much or as little as they wished; the final choice was theirs alone. The patient could make notes on the 'menu' prior to the crisis planning meeting. The options are listed later in Table 2. The card was designed in such a way as to fold neatly into a plastic cover small enough to be carried in a purse or wallet.

Drawing up the card: the crisis planning meeting

A crisis planning meeting was arranged to which the patient, keyworker and relevant psychiatrist were invited. The patient was encouraged to invite anyone else who might be helpful. The aim of the meeting was to have an informed discussion of the information or crisis plan to be included on the card. The Southwark Independent Advocacy Service agreed to offer advocacy. The crisis planning meeting was facilitated by one of the researchers (K.S.). Each menu heading and the entries made were discussed with the final wording agreed by the patient. Finally the clinical team decided whether the selected items described an acceptable crisis plan and should therefore be called a 'joint crisis plan'. If not, the selected items would be prepared as a declaration of the patient's wishes and called a 'crisis card'.

Follow-up

A semi-structured follow-up interview with patients completing a card was conducted at 1 month and at 6–12 months by researchers (C.J. and S.W.) acting on behalf of the Community Health Council (an independent patient 'watchdog'). The aim was to evaluate whether the users perceived the process to have been coercive, and to collect information on the practical use and possible psychological value of the card. Additional information was also obtained from keyworkers, case-notes and the Emergency Clinic (a 24-h, 7 day a week emergency service based at the Maudsley Hospital). Changes in admissions for those patients with a card, comparing the 2 years prior to use of the card to the year after, were examined by means of the hospital's record system.

Results

Users wanting a card

Of 106 users who fulfilled the study criteria, 42 subjects (40%) wished to participate in the project, but two were unable to complete their card due to readmission. Lack of insight or an unwillingness to acknowledge the possibility of future relapses were the most common reasons for refusal (15). Only a small proportion of patients raised concerns about the implications of carrying confidential information on their person (4). The sociodemographic and diagnostic characteristics of participants ($n=42$) and non-participants ($n=64$) were compared. There were no significant differences ($P<0.05$) between the two groups on the following variables: age; sex; education; marital status; living alone; type of accomodation; place of birth; employment status; total number of admissions; history of violence; or involuntary admission. Users who wanted to develop a card were significantly more likely to be white ($\chi^2=4.80$, $P=0.03$), to suffer from an affective psychosis ($\chi^2=9.96$, $P=0.002$), to have a longer duration of illness ($P=0.022$, 95% CI 0.74, 9.31), and to have made suicide attempts or to have been assessed as being at risk of suicide at some time during their illness ($\chi^2=5.13$, $P=0.024$).

Table 1. Characteristics of users who fulfilled the study criteria that predicted a wish to develop a crisis card or joint crisis plan when examined by logistic regression

	Adjusted odds ratio	Confidence interval (95%)		Probability
History of suicide attempts or risk	2.84	1.13	7.14	0.026
Diagnosis (affective psychoses)	3.80	1.51	9.55	0.004
Frequency of admission (less than annual admissions)	3.96	1.25	12.55	0.019

Although there was no significant difference in the total number of lifetime admissions, those users with less frequent admissions (less than annual admissions) were more likely to consent. When these variables were examined by logistic regression, the two groups differed on three variables, namely diagnosis, frequency of admission, and a history of suicide attempts/assessment as having been a suicide risk (Table 1).

In total, 40 users completed a joint crisis plan, and none finally opted for an independent crisis card. On one occasion there was significant disagreement with the clinical team over a user's wish for an advance statement refusing ECT. The patient did not wish this to be called a crisis card (indicating that this was the user's view alone), but preferred the team to include a statement of their disagreement about this specific issue, and to call the resulting card a joint crisis plan (indicating the collaborative nature of the overall plan).

Content of joint crisis plans

The frequencies with which users included the possible options on the card are listed in Table 2. The three most commonly included elements of the current care plan were mental health problem or diagnosis (95%), current medication (93%) and first signs of relapse ('What happens when I start to become unwell') (93%). A total of 36 users (90%) made a statement about what should be done at the first signs of relapse, of whom 30 users requested contact to be made with their treatment team as soon as possible, either alone (8) or in combination

Table 2. Frequency with which users chose to include options on their completed crisis card or joint crisis plan

	Frequency of inclusion on card/plan	
Wording of section on completed crisis card or joint crisis plan	%	(*n*)
Contact details		
User's name, address/telephone no.	100.0	(40)
GP's name, address/telephone no.	90.0	(36)
Consultant/name of team, address/telephone no.	100.0	(40)
CPN's name, address/telephone no.	87.5	(35)
Social worker's name, address/telephone no.	12.5	(5)
Other name, address/telephone no. (total cards with one or more, e.g. probation officer)	27.5	(11)
Nominee's name, address/telephone no.	82.5	(33)
Current care and treatment plan		
My mental health problem or diagnosis	95.0	(38)
Physical illnesses or allergies	35.0	(14)
My current care/treatment plan	77.5	(31)
Current medication and dosage	92.5	(37)
Circumstances that may lead to me becoming unwell or which have done so in the past	65.0	(26)
What happens when I start to become unwell	92.5	(37)
Treatments or other things that have been helpful during crises or relapses in the past	77.5	(31)
Care in a crisis		
What I would like to be done when I first start to become unwell	90.0	(36)
Preferred treatment or social care during a crisis or relapse	65.0	(26)
Specific refusals regarding treatment during a crisis or relapse	52.5	(21)
Circumstances in which I would wish to be admitted to hospital for treatment	70.0	(28)
Practical help in a crisis		
If I am admitted to hospital please contact the person named below and ask them if they would carry out the following tasks for me (e.g. check my home is secure)	52.5	(21)
If I am admitted to hospital I would like the following arrangements for my children/dependent/relative	5.0	(2)
Other information I would like to be known or taken into account (e.g. special diet, people to be told/not told, etc.)	20.0	(8)
Agencies or people that I would like to have copies of this card or agreement		
Myself	100.0	(40)
Treatment team	100.0	(40)
Emergency clinic	85.0	(34)
General practitioner	72.5	(29)
My nominee	75.0	(30)
Other	52.5	(21)

with further specific statements about their initial care (22). In total, 26 patients (65%) made a statement about treatment preferences if a full relapse could not be prevented; 21 patients (53%) made an advance refusal of a specific treatment. Specific drugs or combinations of drugs were most commonly refused because of side-effects. No patient made a statement refusing all drugs, or all classes of drugs (e.g. all antipsychotics). Haloperidol was most commonly refused (7), followed by chlorpromazine (5). In total, 28 patients (70%) made a statement regarding the circumstances in which they should be admitted.

Follow-up

A total of 37 users (93%) participated in follow-up interviews at 1 month and at 6–12 months, and 19 out of 20 keyworkers (95%) were interviewed at 6–12 months.

Use of card in a crisis. A 'crisis' had been experienced by 26 patients by the 6–12 month follow-up, usually a relapse of symptoms or a major life event. For 19 (73%) of the 26 patients who had experienced a crisis, the card was consulted. A total of 16 patients had at least one psychiatric admission during the study period, and for 13 patients (81%) the card was used during at least one admission. The card was considered to have been helpful in 14 (74%) of the 19 crises as reported by either the user or the keyworker. The ways in which cards were used were described as follows.

(i) *Provision of information.* The provision of contact information for informal and formal carers together with information on current care and treatment was of particular use for patients who came into contact with the police (3), or who became unwell outside their local service catchment area or had to be placed in outlying hospitals (6). Some described non-crisis usage of cards as a reference for contact numbers which improved access to the service, and as a reminder of their medication.

(ii) *Assessment of previous crises.* The recognition and recording of what has helped or not helped in a crisis and recognition of triggers for relapse or first signs of relapse were reported to facilitate early recognition and appropriate crisis management for both users and carers. The cards appeared on occasion either to avert unnecessary admission or to facilitate an appropriate early admission (see 'admissions').

(iii) *An advocacy tool for crisis.* Formal advocacy services are rarely able to respond in an emergency. Although the original aim of the voluntary sector crisis cards was to provide emergency advocacy from a friend or relative, most users in our study appeared to want their nominee to be available to support them in a crisis rather than to advocate for them in the strict sense. In 10 cases the user's nominee was contacted as instructed on the card and attended during a crisis.

(iv) *Advance plans for care in a crisis.* Advance plans were often a combination of personal directions (e.g. I will take medication X and sit with a neighbour) and directions for services (e.g. I do not wish to have medication Y). No dissatisfaction with adherence to any of the statements regarding treatment preferences or admission to hospital was expressed in follow-up interviews with users. Of the 21 users who had made refusals of specific treatments, nine were admitted, and for 8 users the requests were met without difficulty.

Users' views of the process and psychological value of card. At the 1-month follow-up, 35 patients (95%) felt that they had been able to voice disagreement freely at the crisis planning meeting, and 32 patients (92%) said that the final joint crisis plan adequately reflected their wishes (the remaining 3 patients (8.3%) were unsure). Table 3 shows that users felt more involved in their care, more positive, and more in control of their mental health problem as a result of developing the card. Two-thirds of users carried their cards with them on most days or every day at the 6–12 months follow-up. In total, 30 (81%) of the 37 users said they would recommend the card to other users, whilst 17 (90%) keyworkers would recommend the card to other services.

Table 3. Percentage of users replying definitely or probably 'yes' (on a response option scale ranging from 'definitely no' to 'definitely yes') to the following questions

	1-month follow-up (*n*=37) % (*n*)	6–12 months follow-up (*n*=37) % (*n*)
Has developing your crisis card or joint crisis plan made you feel more involved in your care?	78 (29)	57 (21)
Has developing your joint crisis plan helped you feel more positive about yourself or your situation in any way?	51 (19)	60 (22)
Has developing your joint crisis plan made you feel more in control of your mental health problem?	62 (23)	51 (21)
Do you feel more likely to continue with your care/treatment as a result of developing your joint crisis plan?	51 (19)	41 (15)

Problems encountered. We identified two main problems.

(i) *Stress of developing the card.* As the process of developing a card involved reviewing the diagnosis, past crises and the possibility of further relapses, we were aware that this might prove difficult for the patient. Keyworkers reported that 12 users apparently found the crisis planning meeting stressful, but only 6 users reported this themselves. One patient with a history of frequent and prolonged admissions for manic-depressive psychosis experienced early symptoms of relapse which might have been precipitated by the meeting, but used the plan on her card and recovered without requiring admission. She considered the confidence gained from this experience to be one of the factors in her subsequent prolonged remission.

(ii) *Management guidelines not followed or treatment refusal overruled.* Two of the three users who declined to be interviewed at follow-up had experienced problems with management guidelines not being followed or being overruled. The first incident involved a woman with a history of rapid onset of episodes of mania. Her father was unable to arrange a home visit over a weekend (as agreed in the joint crisis plan) when she next relapsed, and her keyworker felt that her subsequent admission was inappropriately delayed and complicated. The second incident involved a man who suffered from mania with a history of serious violence, whose card refused haloperidol treatment. He presented to the Emergency Clinic as planned, in a hypomanic state, initially requesting admission but later refusing. After a prolonged wait in the clinic he became irritated and assaulted a nurse. Although staff had consulted his card, he was given haloperidol because of the seriousness of the emergency.

Both incidents occurred early in the study period. It seems that at this early stage acceptance of the validity of the instructions was only partial. On both occasions it would have been feasible to carry out the instructions, and the effect of not doing so undermined confidence in the project (both patients refused follow-up), and may have reduced confidence in their clinical team (although they remained in treatment).

Admissions. During the 2 years prior to developing a card, there were 88 admissions for this group of patients, i.e. an average of 44 admissions per year. Using the hospital's patient administration system to examine the year following the development of the card, there were 31 admissions, i.e. a 30% reduction. There was no overall reduction in admissions in the community directorate of the hospital.

Discussion

Although crisis cards were introduced by users' groups as early as 1989, to our knowledge this is the first descriptive study of the development and use of a form of crisis card. This study provides preliminary evidence of both practical and psychological benefits of a collaborative form of crisis card, or joint crisis plan. The study was not controlled, and the 30% reduction in admissions may in part be explained by a 'worst year' effect as patients were required to have had at least one admission in the preceding 2 years. Validated rating instruments were not used because the main aim of this pilot study was to assess the feasibility of the process and potential areas of benefit. However, given the fact that the patients selected for this study suffered from chronic severe psychotic illnesses with many previous admissions and a high risk of relapse, the potential benefits of this relatively cheap and safe intervention warrant further investigation in a larger controlled study using validated measures.

Unfamiliarity with the concept of crisis cards among users and staff probably explained the slow initial recruitment rate among users. Concerns about whether the process of developing individual cards would be coercive, or whether the cards would have any value, may also have played a role. As the study advanced we observed a progressive increase in interest and acceptance by both staff and users, and an increased rate of recruitment; further cards would very probably have been developed if the study period had been extended. It was our impression that this was due to both users and staff being reassured about the process of negotiation and the content of the cards, and subsequently recommending them to others. A facilitator who was independent of the clinical team and who could be relied upon to enable the user to exercise choice was important, as was the opportunity to invite supporters or an advocate. All of the participants opted for 'joint crisis plans' rather than crisis cards. This reflected a successful dialogue between patient and treatment team, which was perhaps likely to occur among users who were interested in collaborating with what was, after all, a service-led initiative. More patients might have chosen 'crisis cards' had the project been user-led, and perhaps a largely different group of users might have participated. We were unable to assess the impact of exposing unresolved disagreement between staff and patient which may potentially compromise the therapeutic alliance.

The impact of working collaboratively with patients with long-term psychotic disorders in a way that enhances their autonomy, sense of self-mastery or sense of being able to control their illness or treatment has been proposed to have a beneficial influence on quality of life (8, 9), psychological functioning (10–12), attitude to treatment (13) and rate of hospitalization (14). Crisis cards were originally developed by the voluntary sector in order to exercise user empowerment, a process which can be seen as analagous to the concepts of gaining greater autonomy and control. Although user empowerment is sometimes viewed as of necessity being in opposition to the psychiatric services (15), our results show that joint crisis plans developed collaboratively with patients in a non-coercive setting enhanced the patients' sense of control.

The collaborative development of a joint crisis plan with patients is a novel form of psychosocial intervention. This preliminary evidence suggests that, in addition to the direct, practical effects on recognition of relapse and crisis management, a range of beneficial effects on psychological functioning and quality of life may emerge, mediated through improvements in understanding, perceptions of control, and acceptance of the illness and treatment.

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