Illness careers and continuity of care in mental health services: A qualitative study of service users and carers

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ABSTRACT

Continuity of care is considered by patients and clinicians as an essential feature of good quality care in long-term disorders, yet there is general agreement that it is a complex concept and the lack of clarity in its conceptualisation and operationalisation has been linked to a deficit of user involvement. In this paper we utilise the concept of the 'patient career' to frame patient accounts of their experiences of the mental health care system. We aimed to capture the experiences and views of users and carers focusing on the meanings associated with particular (dis)continuities and transitional episodes that occurred over their illness career. As part of a large longitudinal study of continuity of care in mental health a sub-sample of 31 users was selected together with 14 of their carers. Qualitative interviews framed around the service user's illness career explored general experiences of relationship with services, care, continuity and transition from both user and carer perspectives. Five key themes emerged: relational (dis)continuity; depersonalised transitions; invisibility and crisis; communicative gaps and social vulnerability. One of the important findings was the fragility of continuity and its relationship to levels of satisfaction. Supportive, long-term relationships could be quickly undermined by a range of factors and satisfaction levels were often closely related to moments of transition where these relationships were vulnerable. Examples of continuity and well managed transitions highlighted the importance of professionals personalising transitions and situating them in the context of the daily life of service users. Further research is required to identify how best to negotiate these key points of transition in the future.

Introduction

Continuity of care has become an important aim of health policy and service delivery (Department of Health, 1990, 1995, 2001) as well as a key criterion for service evaluation (Johnson, Prosser, Bindman, & Szmukler, 1997). Yet, it is generally agreed that the concept has lacked systematic definition (Crawford, Jonge, Freeman, & Weaver, 2004; Freeman, Shepperd, Robinson, Ehrich, & Richards, 2000) and, as Haggerty et al. (2003) emphasise, without clear definitions policy solutions are likely to remain elusive. Early conceptualisations of continuity of care tended to equate it with continuous care by the same person or persons. Over time this gave way to a view of continuity as involving the coordination of the patient's progress through the system (Adair et al., 2003). By the early 1990s it began to be seen as a potential measure of system-level reform.

In recent years research on continuity has proliferated in a variety of health care settings. Operationalising the concept has proved difficult and in relation to mental health services researchers have highlighted differences in continuity at discharge (Sytema & Burgess, 1999; Sytema, Micciolo, & Tansella, 1997); as well as cross-boundary continuity between primary and secondary care (Bindman et al., 1997), psychiatric and emergency services (Heslop, Elsom, & Parker, 2000), and inpatient and community settings (Kopelowicz, Wallace, & Zarate, 1998). Others have focused

on particular features of care including: 'a sustained patient–physician partnership' (Nutting, Goodwin, Flocke, Zyzanski, & Stange, 2003); maintenance of contact, consistency in the member of staff seen and success of transfer between services (Johnson et al., 1997); and 'adequate access to care… good interpersonal skills, good information flow and uptake between providers and organizations, and good care coordination' (Reid, Haggerty, & McKendry, 2002). Discontinuity has been defined as gaps in care (Cook, Render, & Woods, 2000). A systematic review of the literature found that continuity of care has been defined in terms of service delivery, accessibility, relationship base and individualized care (Joyce et al., 2004). In contrast, qualitative studies have found that service users emphasise the importance of building a long-term relationship with a professional and express frustration at having to repeatedly review their medical histories during transitional periods (Kai & Crosland, 2001). And while there are apparent differences between professionals' and service users' views over what constitutes continuity and the most appropriate sites for care, users describe having to engage in tactics such as 'acting up' in order to gain appropriate services (Lester, Tritter, & Sorohan, 2005). Reviews of continuity of care studies have linked the lack of clarity in its conceptualisation and operationalisation to a deficit of user involvement (Freeman et al., 2000; Ware, Tugenberg, & Dickey, 1999). In response, researchers have proposed a 'multi-axial definition' of continuity of care for mental health comprising: experienced, cross-boundary, flexible, information, relational, contextual, long-term and longitudinal (Freeman, Weaver, Low, de Jonge, & Crawford, 2002). Others have emphasised that continuity of care is best understood as a multidimensional concept (Bachrach, 1981). Here researchers have combined factors such as breaks in service delivery with the experience of care, maintenance of contact, consistency in the member of staff seen, transition and integration between services, adherence to service plans, and management of service users' needs (Crawford et al., 2004; Johnson et al., 1997). Domains of continuity have been proposed including: knowledge, flexibility, availability, coordination and transitions (Ware, Dickey, Tugenberg, & McHorney, 2003). These approaches, coupled with a view of continuity as involving the coordination of the patient's progress through the system (Adair et al., 2003), resonate strongly with the notion of a patient career.

In this paper we utilise the concept of the 'patient career' to frame patient accounts of their experiences of the mental health care system. We follow Hughes's (1937) definition of a career as a series of movements between stages in a sequence and its use in relation to patient experiences in mental health institutions (Goffman, 1970). A number of studies have utilised the concept in mental health settings to highlight the relationships that are formed and changed as individuals negotiate the system (Gove, 2004), and the changes that occurred to patient pathways as a consequence of de-institutionalisation (Pavalko, Harding, & Pescosolido, 2007). As Pescosolido (1991) argues, individuals negotiate illness career pathways drawing on social networks and ties in the context of their social location and their health beliefs and the study of such illness careers requires longitudinal, multi-method and analytically flexible approaches. In this study we aimed to capture the experiences and views of users and carers focusing on the meanings associated with particular (dis)continuities and transitional episodes that occurred over their illness career. The interviews explored general experiences of relationship with services, care, continuity and transition from both user and carer perspectives.

Methods

As part of a large longitudinal study of continuity of care in mental health, 180 service users diagnosed with long-term psychotic disorders and 98 service users diagnosed with non-psychotic disorders were sampled from the caseloads of seven Community Mental Health Teams (CMHTs) covered by two mental health trusts (Burns et al., 2009). CMHTs are multi-disciplinary teams in which the care of each patient is managed by a key worker (who might be a community psychiatric nurse, occupational therapist or social worker) with contact with a consultant or more junior psychiatrist. The inclusion criteria were diagnosis (whether of psychotic or non-psychotic disorder) received at least 2 years previously, on the caseload of the CMHT for at least 6 months, on the enhanced level of the Care Programme Approach and aged 18–65 (inclusive). Being on the enhanced level of the Care Programme Approach means that the patient should have their case coordinated by a key worker with whom there should be regular contact. Sampling was stratified to ensure 25% were from minority ethnic groups. Analysis of survey data from this longitudinal survey identified nine components of continuity by means of a factor analysis and these were used as a basis for identifying individuals for the qualitative study.

Sample

For this qualitative study a sub-sample of 31 users was selected from the larger longitudinal study together with 14 of their carers. Service users and carers were sampled theoretically and purposively using factors derived from the quantitative survey of the full sample in order to capture the experience and views of people for whom continuity of care had been particularly complex or problematic (for instance, because of multiple referrals, or changes of personnel or needs). Lists were drawn up of users scoring highest and lowest in each of the continuity factors generated by an early iteration of the factor analysis of the quantitative survey. The original nine factors used are detailed in Table 1 together with the distribution of the two sets of users across high and low scores by gender.

Where possible, users with carers were selected, but the purposive sampling method aimed at an even distribution across gender, age and NHS Trust. For the cohort with psychotic disorders the number of available respondents in each factor ranged from 4 (low Factor 3) to 21 (high Factor 3). For the cohort with non-psychotic disorders, potential respondents varied in each of the sub-factors (high and low) from 3 (low Factor 4 and low Factor 6) to 13 (high Factor 7). The final sample consisted of 20 users and 10 carers in the cohort with psychotic disorders and 11 users and 4 carers in the cohort with non-psychotic disorders. For the group with psychotic disorders, there were 11 males and 9 females. All of the carers interviewed were female; six were mothers of the user, three were wives and one was a community psychiatric nurse (the user nominated this person as a main carer). The mean age of users was 42 with a range of 27–72. For the group with non-psychotic disorders there were nine females and two males. Of the four carers interviewed, one was female (mother) and three were male (long-term partner, husband and friend). The mean age of users was 49 with a range of 29–59. The greater proportion of female participants in the non-psychotic disorder group reflects a higher proportion of women in the larger survey in that group (psychotic disorder sample population 44% female; non-psychotic disorder sample population 67% female). However, the socio-demographic distribution of our qualitative sample does mean that the generalisability of our findings should be treated with caution.

Interview schedule

A semi-structured interview schedule was developed with the aim of guiding the interview towards discussing the user's career as a patient, looking at their history of contact with mental health services. We used an adapted life grid approach (Berney & Blane,

Table 1
Factors used in the sampling strategy and distribution of service users (based on an early iteration of the factor analysis presented in Burns et al., 2009).

Factor	Description	Low	High
1	*Regularity* – high score means: being seen more regularly by fewer different non-medical staff.	PD (F) NPD (F)	PD (F)
2	*Experience & relationship* – high score means: good therapeutic relationship, high experienced continuity and a low number of needs of which more than 90% are met.	PD (F) NPD (F)	PD (M) PD (M) NPD (F)
3	*Consolidation* – high score means: fewer transitions or referrals to other agencies.	PD (F)	PD (M)
4	*Flexible continuity (response)* – high score means: CMHT response to deterioration (increase in contact frequency), while low score means no response leading to hospital admission.	PD (M) NPD (F)	PD (F) NPD (F)
5	*Long-term continuity (primary care contacts)* – high score means: not having long gaps between contacts and not seeing a primary care professional	PD (F) NPD (M)	PD (M) NPD (M)
6	*Information continuity (medical)* – high score means: seeing only one or two psychiatrists and more letters being coped to users.	PD (F) NPD (F)	PD (M)
7	*Supported living* – high score means: attending day care and living in supported accommodation.	PD (M) NPD (F)	PD (M) NPD (F)
8	*Longitudinal continuity (medical)* – high score means seeing few different psychiatrists regularly (1 or 2) and either having no care-coordinator or more than 2.	PD (F) PD (M) NPD (F)	PD (M)
9	*Cross-boundary continuity (personal relationships & information)* – high score means: seeing a known CMHT member when hospitalized and having transitions documented.	PD (F)	PD (M)

PD = psychotic disorder; NPD = non-psychotic disorder; F = female; M = Male.

1997; Dex, 1991) by allowing users to talk freely in conversation about their experiences starting from their first encounter with mental health services and making links to particular life events and episodes as they arose. Following the interview, a patient career chart was drawn up based on the interviewer notes and this was appended to the interview transcript. As an illustration, Fig. 1 gives an example of a section from a career chart (the chart has been edited to maintain anonymity).

Interviews were undertaken between October 2005 and September 2006. For the most part, users were interviewed in the same location as they had been interviewed in for the quantitative study, at a site convenient for them. For the majority (85% of cases) this was the user's own home, with the remainder being undertaken in a range of locations including assisted accommodation and designated rooms in CMHT bases. Where carers were interviewed, wherever possible the user was interviewed alone first. In two instances, however, the user and carer interviews were conducted jointly at the request of the user. On average, interviews with users lasted approximately 1 h and carer interviews approximately 40 min. All interviews were recorded and independently transcribed. The transcripts were then checked against the tape by the interviewer and were formatted to include a synopsis of the interview content as well as the interviewer's field notes and demographic information on each respondent.

Ethics

Ethical approval was obtained from two Local Research Ethics Committees. Written informed consent was obtained before all interviews. Users and carers were recruited from the larger longitudinal survey (Burns et al., 2009) and consented again for this qualitative study. Consent was treated as a continuous process and the interviewer followed a protocol giving guidance on the available support for users and careers should they become distressed.

Patients were advised that they could terminate the interview at any point and that participating in the study would not affect their treatment in any way.

Analysis

Interviews were independently transcribed and entered into MAXQDA (MAXQDA, 2001). Following initial familiarization with the data, a thematic analysis was undertaken whereby an initial coding scheme was developed and indexing undertaken through constant comparison within and between cases. Transcripts were coded by the interviewer (author 2) and categories developed, refined and validated in collaboration (author 2 and author 1). All names used in the presentation of findings are pseudonyms. Users and carers are identified indicating whether user (U) or carer (C) and diagnosed with psychotic disorder (A) or non-psychotic disorder (B). Carer numbers are matched to user numbers.

Findings

Five key themes emerged: relational (dis)continuity; depersonalised transitions; invisibility and crisis; communicative gaps and social vulnerability. One of the important findings was the fragility of continuity and its relationship to levels of satisfaction. Supportive, long-term relationships could be quickly undermined by a range of factors and satisfaction levels were often closely related to moments of transition where these relationships were vulnerable.

Relational (dis)continuity

Service users mostly provided accounts of their illness career that emphasised repeated changes of staff. This appeared to be a major area of discontent with services for both users and carers.

"I've had loads [keyworkers]. I mean I got like a nurse at the hospital, C__, I've had her about six months. Before that I was with another guy, before that another bloke, another woman, another… it always changes, that's what I don't like, you know." [UA13, male, 27 years, schizophrenia]

The changing relationship with providers sometimes left users feeling helpless and isolated. Even when users were informed about staff changes and there was not a wait for a new key worker, it still took time to build up a relationship. Carers also voiced their frustration at the emotional demands this put upon users.

"… they change all the time, every few months they seem to change. So as soon as I get to know one, then they've gone…It used to be very upsetting, very disruptive, because every time there was a new doctor or a new key worker or a new social worker, or whoever, you've got to start right from scratch; even though they've got a file which is kind of this thick, you know? They will still sit and ask him questions and he feels he's just got to repeat his whole lifestyle all over again, you know, every few months to whoever is new! So, that can be very frustrating." [CA13, carer of son with schizophrenia]

The frustration with having to re-tell the story was a common feature of relational discontinuity. This re-telling was sometimes referred to as becoming 'automatic' and in the re-telling could lead to a sense of de-valuing the user's experiences. For service users with non-psychotic diagnoses, changes in psychiatrists were very common but this was felt less keenly because users usually had less contact with them. Nevertheless the frustration that accompanied having to repeat personal circumstances was commonly expressed,

YEAR	MENTAL HEALTH	SERVICES	GENERAL
1994	Psychosis (age 25)	Five days in hospital. Discharged with medication	Mother moved in. Gives details of side effects from medication Breaks up with girlfriend
1995	Mother called police – wanted to have him admitted.	Psychiatric hospital (A) for two months then moved to assisted accommodation	Describes incident and police involvement
2000	Cut dosage to half strength	Getting repeat prescriptions from GP	University for two years but left because feeling ill again
2002	Third admission	Psychiatric hospital (A). Started seeing CPN regularly after discharge because of medication change.	Describes incident leading to admission. First time of recalling a diagnosis of schizophrenia. Back in assisted accommodation.
2005	Under CMHT	Moved to new assisted accommodation. Saw psychiatrist for first time since discharge re: medication change.	I don't need to access services "I just get my depot". Can't wait to get out of this accommodation. Still concerned about side-effects

Fig. 1. Anonymised sample from a career chart.

with some users *anticipating* a transient relationship on the basis of previous experiences. For many users whose illnesses stemmed from difficult past experiences this was highly distressing.

"that is one of the most awful things about being a patient in this system, is that you find yourself having to repeat and repeat things that are so traumatic for you, and especially for somebody like me who's probably … I mean, I am a deeply private person, […] I'm paranoid about the evidence that's contained in my files that it's accurate and who has access to it, etc., and I've found it deeply distressing because you become desensitised, you become objectified yourself! You know, all of a sudden you no longer are the subjective person with your experiences; you've objectified yourself and you're having to sit there and trot out this stock story. The number of times I've had to sit there and say, 'Yes,' (like I have today), 'I have clinical depression, and I have personality disorder, my mother has manic depression, and my father … my brother has der-der-der … me, me, me, me, me, me, me!' And that is really, really, really quite … it's almost like a second form of abuse in a way, to you as a patient, you're totally divorced from your experience and you become an objectified set of symptoms and a diagnosis, you know! And people see the diagnosis and they don't see the person, and you don't feel validated, you don't feel that your experience is at all validated."
[UB9, female, 40 years, personality disorder and depression]

On the whole, users were very satisfied with their key workers and built trusting relationships with them. Their main point of dissatisfaction was the short-term nature of these relationships.

Where there were problems with key workers, users were not always aware of their rights. Having experienced gaps between key workers, they were sometimes reluctant to complain in case this meant not having any support. Indeed, users in both the groups, if dissatisfied with their key worker, tended simply to wait till the key worker had left. Their experience of changes in key workers over the course of their illness careers meant that they were all too aware that their current worker would not remain for too long.

Depersonalised transitions

The transition between providers, particularly for those changing teams, was often a confusing time. Three main types of transitional experience were identified: transition at discharge, transition between teams following the user's change of residence and transition between teams as the teams underwent restructuring. For each type individuals recalled examples of 'good' and 'bad' transition but emphasised the importance of personal relationships. For example, in relation to transition at discharge poor personal communication was related to confusion over status.

"At the moment, I just recently found out that I was sort of discharged from the hospital, because I hadn't seen the psychiatrist or anything for about two or three years, and I wanted to see one…I mean the only contact I have is with the nurses that do my injection. And like I say, I went to see the doctor, I thought I could just book an appointment, but they said I had to go through my GP, which I found a bit sort of … not

upsetting, but, you know, I felt as though if I need to see a doctor, I should be able to see one, you know, fairly quickly."
[UA8, male, 52 years, bipolar disorder and schizophrenia]

The number of hospital admissions over the course of illness careers varied from one admission to 11 (with one user reporting too many to remember). For some the hospital offered a place of calm and respite during their most difficult times but the transition at discharge was a key point of vulnerability where, having kept to a strict routine during their period of stay, after discharge they were left to cope on their own and fill that time independently. For carers also the need for more advice and information on discharge processes was emphasised as often the families were not kept informed over a user's status.

Carers also emphasised the importance of a personal relationship and the dangers that a transition posed for this 'personal' touch. For example with respect to a transition following a house move:

"We were looked after by the X team and they were brilliant. And we had a very good CPN [community psychiatric nurse], you know, and we could always approach him, and he would come and visit. You always knew there was somebody at the end of the phone if you needed them. We are not quite finding the same level of care with the Y team, although they are trying to establish somebody now that we can contact. But it's extremely important to have a personal relationship with a CPN, absolutely vital. It's my number one priority… but we're *on unknown territory* with the X team, we don't feel quite as well cared for, and really we haven't established any proper personal contact yet, you know. So I feel that really we're left dangling. It's an absolutely vital lifeline to have somebody that knows you, that listens to you, that responds to you, at the other end of the phone. It's absolutely vital."
[CA11, carer of husband with schizophrenia]

Although transitions were highlighted by carers as particularly stressful and problematic, there were examples of transitions that were supportive and appeared to ensure good continuity. In these cases, there appeared to be a stronger emphasis by professionals on personalising the transition and situating it in the daily life of the user. This is an example of a user discussing a transition following a restructuring of services:

Interviewer: So, how was that?
It was good, because they sort of dovetailed it really well, my old OT [occupational therapist] and my new OT dovetailed it; they met, they corresponded, er, before they met so they knew who I was and what my diagnosis was, and what I was like, what my life was like. So, er … and when asked if I would need a consultant on my new team, my old OT and new OT said, no, just an OT would be fine, so it worked really well. We had a meeting here that day, because I only moved in here a year and half ago. The day the carpets was laid was the day that the old OT and new OT and myself were meeting for the first time, so they were all thankfully laid and we then met in the kitchen! *(laughs)* So it worked out really well.
[UA9, female, 42 years, bipolar disorder]

Responses to transitions varied with some users being able to cope with change while others found even small disruptions difficult to respond to positively. UB4, however, spoke at great length of her distress at the prospect of having her key worker 'taken away' and in particular the impact this had on levels of *trust*:

I'm just coming to what I call the crux of my treatment and they've taken away the one person that I trust. Now, erm, I'm keeping on with her at the moment, every two weeks until August, er, and then she's got to pass me over; she has no choice. Erm. And I'm not happy, because I mean, have I got to spend now

another 18 months trying to build up a rapport with somebody else? What if I don't like that person? What if I don't trust that person? I'm back to where I started from, out on a limb again, and I think this is very, very unfair of the mental health service to do this to people.
[UB4, female, 58 years, cyclothemia and behavioural disorder]

Invisibility and crisis

Both service users and carers voiced concerns about services being centred around responding to crises rather than preventative support. There was a feeling that being perceived as 'well' or 'functioning' resulted in invisibility. For example, UA6 felt that her relative stability had meant that services were less geared to offering support. She emphasised that although she might not act out a suicide attempt she still required support.

"I don't have a drink problem or a drug problem, or I don't harm myself, and I wouldn't do any of those things. So as far as they're concerned, what's the problem? I'm not going to hurt myself or anybody else, so there's no urgency as far they're concerned. Whereas, I have said to them before, 'do you think I don't feel suicidal sometimes?' because I really do. But I know that I'd not do it, and so do they. So as far they're concerned, I'm coping with it."
[UA6, female, 35 years, schizophrenia]

UA6's mother and carer concurred, and further believed that because she was known to be caring for UA6, that gave services an extra motive for reducing support to UA6.

But, we know what happens – until someone's in absolute crisis, it, you know, they don't get to the top of the list, because the resources aren't there. And she didn't always seem to be maybe as seriously ill as perhaps someone else just down the road. And quite honestly I have sometimes felt that because it was known that there was somebody there keeping an eye on her, she was maybe less of a priority than somebody who had nobody to keep an eye on them.
[CA6, carer for daughter with schizophrenia]

Non-psychotic service users echoed the sentiments of the group with psychotic disorders with regards to services being focused on crisis cases and the sense of being invisible or abandoned until a crisis point was reached. UB9 had experience of being a carer as well as a patient, her mother and brother both having severe mental health problems as did an ex-partner. She voiced her frustration at this:

"The only time that anybody jumped was the day I rang them up, I said, 'Right. He's now taking the house apart. He's been out on the street challenging people with a knife!' and then, boof … jump! Suddenly there's an ambulance at the door, there's a social worker and …! You couldn't get anybody interested in the weeks running up to that crisis, you know, which to me is appalling, when preventative action could be taken and it's not.
[UB9, female, 40 years, personality disorder and depression]

Communicative gaps

Accounts gave the impression that the communication between different services was not always seamless and often it was left to the user or the carer to try and keep all agencies abreast of changes. This was further hampered by the high turnover of staff making it difficult to know who to contact. There were also communicative gaps between users and their carers and communicative gaps

between services and carers that appeared to be centred around the ambiguous status of carers. Most of the disparity between user and carer reports were around the effectiveness of changes in medication regime which became a site of conflict. Discharge from hospital was again a key point where gaps in continuity could appear and communication gaps appeared to be a significant part of this:

"The first time, it was a complete disaster. Erm, he was discharged on a Bank Holiday; he phoned me and said he was discharged, erm. I couldn't get hold of a member of staff to have that confirmed so I went to pick him up, and there was no real member of staff; they just sort of said, 'Oh, yes, if he says so, then he can go!' And I asked about medication and they said, 'Oh, the pharmacy's shut because it's a Bank Holiday!' So eventually I kicked up and they did manage to find half a dozen tablets and put them in an envelope for me to take home for the weekend. And I bought him home and I said, well, what now? Should we contact anybody? And nobody really had any idea. So we got through the weekend, and I managed to contact his key worker on the Tuesday, I think it was, after the Bank Holiday. And she was horrified, because nobody had even been told, there'd been no discharge meeting, there'd been nothing. So again, I was quite appalled that, you know, I should be allowed to just go and pick him up, and nobody was even aware that he was out in the community, under no care again."
[CA13, carer of son with schizophrenia]

Social vulnerability

Many users gave accounts of their illness careers that highlighted their social vulnerability. The complexity of their needs and the uncertainty surrounding their illness and daily lives had consequences in terms of their reliance on carers and key workers. Users had a sophisticated understanding of social vulnerability as implying that an individual is under threat of harm caused by the omissions, neglect or positive actions of others. Support in negotiating the complex world of benefits, employment and housing needs appeared to be a key element of providing continuity. Furthermore, problems in these social areas could have negative effects on perceived levels of continuity. The main needs identified by users and carers were greater continuity of key workers and need for more information and support in accessing the 'system'.

I was reliant on [my key worker], erm, and she didn't know herself, so I mean it was … you know, she sort of suggested getting in touch with them, and it was … it was my mother, erm, who had to really sort of, you know, find out anything that was going to, you know, come to pass, really, because we had no support in that way, and no understanding of the system, erm, so … yah.
[UB1, female, 40 years, depression and anxiety disorder]

Service users gave a sense of continuity, satisfaction and their own social vulnerabilities being inter-related. They gave positive and negative accounts of crisis services, day centres and social services. The complexity of their needs impacted on their experiences of services. For example, appropriate housing was a major priority for users who were currently or previously on transfer lists and getting safe and secure accommodation was seen as vital to dealing with mental health issues. This illustrated the extent to which social context might influence the experience of continuity or discontinuity. The theme of vulnerabilities was strongly connected with the other themes but the accounts of social vulnerability appeared to go beyond material circumstances to suggest

a relational concept based on potential harm or threats arising from relationships between users and other agents.

Discussion

A number of caveats should be noted as we consider the findings. The interviews were based on service users' and carers' recall of events, some of which were recent while others were not. Recall bias and discrepancies are therefore likely to occur and present problems in terms of accuracy and reliability (Pescosolido & Wright, 2004). The generalisability of the findings should be considered with caution (Payne & Williams, 2005). In particular the experiences of individuals in other parts of the UK may be very different to the accounts from the service users interviewed in this study. The accounts of these service users and carers however resonate with one another and with other qualitative studies (Kai & Crosland, 2001; Lester et al., 2005).

There were commonalities in the experiences of users in both groups with regard to issues of continuity and transition. In both groups, user experiences of continuity varied with some having been with their key worker since their first contact with services (as long as 12 years in one case), to more commonly having numerous key workers who stayed for limited periods of time. Discontinuity with respect to psychiatrists was high, especially as many saw different psychiatrists every 6 months. But with the users with psychotic disorders having spent twice as much time in contact with services as had those with non-psychotic disorders, they were more likely to experience a greater number of changes. Frequent changes to key workers, arising from high staff turnover in the CMHTs, together with the limited contact users had with health care professionals, particularly psychiatrists, meant that they had become experts at condensing their life experiences in order to communicate their entire history of mental health problems in a short time. This led to frustrations with the system and a feeling that their experience was devalued and they were seen as a collection of symptoms. Again this reinforces findings from previous studies (Barham, 1997).

All users and carers spoke about how crucial the relationship with a key worker was and the energy that was invested in that relationship by all parties. Although most had experienced changes in key workers the process never became any easier and for some, the prospect of losing their key worker was devastating. This was linked to a sense of being socially vulnerable. Goodin (1985) argues that social vulnerability is a relational notion that implies that there is some agent capable of exercising some effective choice to cause or avert threatened harm to an individual and Warner (2008) has suggested that vulnerability may be a consequence of the risk based approaches that dominate current mental health service provision. This sense of vulnerability and being reliant on others came across strongly in the accounts in this study. It seemed that where there were strong relationships between key workers and users, these were personalised to the extent that users referred to their key workers as close friends and gave examples of incidents such as sharing hedge trimmers. Transitions were more successful where professionals '*dovetailed*' and they were undertaken in the social context of the user's life, with an understanding of where the user was in relation to other services and needs including housing and support. Research has shown that experiences of mental health services are patterned by gender, class and race (Pilgrim & Rogers, 2005). The relational nature of social vulnerability as a mechanism for reproducing these patterns may be an important area for future research.

Users in both groups complained about the reactive nature of services (which were often quick to respond to a crisis) and the corresponding invisibility of the user and carer in the period

leading up to a relapse or episode. In some cases service providers retrospectively apologised to the users and/or families for not responding fast enough, but this was a repeated pattern and led to users and carers having particular expectations of service levels and contact with health professionals. This crisis-led nature of services meant that those who were relatively stable, or did not display signs of potential risk to self or others felt isolated within services and on the periphery of service delivery. Users and carers desperately wanted services to listen to them more.

Transition between service providers was identified as a source of stress for some users and carers in relation to the provision of appropriate and timely information. Within the wider context of mental health services, it has been acknowledged that the development of multi-agency protocols and guidelines linked to care pathways, together with flexible planning in partnership with users and carers, which incorporates the provision of essential information, is vital to effective transition (Department of Health, 2008). Gaps in communication occurred at a number of levels. Where users relied on more than one provider (supported housing, primary care) there was not always evidence of effective communication between providers and it was often left to the users to fill in each relevant party themselves. There were mixed reviews of hospital stays. Some had found the time beneficial and therapeutic whereas others found their admissions disturbing. Wards often held an array of users with a full spectrum of symptoms and some found this alarming. There were also accounts of violence on the wards including both staff and other users. Many users and their families were not kept informed of expected duration of stay and it was common for carers to report being unaware of the discharge of the user. This adds further support to the findings of Rapaport, Bellringer, Pinfold, and Huxley (2006), who reported that carers found hospitalisation, both during admission and discharge, the one area that was the hardest to access information about.

Carers often felt excluded from the care that services provided. Many felt that they could complement the care that services were providing. The findings support previous work which found that carers felt marginalised by services (Rethink, 2003). Few had an established relationship with a member of the CMHT, reflecting poor practice as carers should receive an annual assessment under standard six of the National Service Framework for Mental Health (Department of Health, 1999). For carers, their frustration at this was compounded by the knowledge that, having been kept on the fringes of the user's care, they would bear the primary responsibility for managing the situation if the user were to relapse or have a difficult episode. Carers spoke passionately about their frustration at not being heard by services especially when they were trying to get some intervention before a crisis. By dismissing carers' accounts, much valuable information was being lost, particularly as the care provided in these circumstances is crucial to the success of government policies emphasising care in the community (Lloyd & Carson, 2005).

Conclusion

This study examined continuity of care from the perspective of service users and carers using participant accounts of illness careers as a way of identifying key moments where continuity might be threatened. An important finding is the apparent fragility of continuity and its relationship to levels of satisfaction. Supportive, long-term relationships could be quickly undermined by a range of factors (including the social context in which users lived their lives). Satisfaction levels were often closely related to moments of transition where these relationships were vulnerable. Key workers whom patients considered their closest confidantes could suddenly leave without sufficient warning, and the devastation experienced would often negate any positive experiences of the relationship they had with their worker and by extension wider mental health services. Examples of continuity and well managed transitions highlighted the importance of professionals personalising transitions and situating them in the context of the daily life of service users. Further research is required to identify how best to negotiate these key points of transition in the future.

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