The Care Programme Approach (CPA) has been used as a patient management framework in mental health care since the early 1990s and is considered good practice. In parallel, the role of informal or family carers in looking after people with mental health issues has been increasingly acknowledged. Although their role and needs were highlighted in the Carers Act 1995, many carers still do not receive the support they need and often feel marginalised.

In 2014-15, a qualitative study involving in-depth interviews with eight carers was conducted at Bradford District Care Foundation Trust to explore the following questions: how do carers view the CPA? What do their views reveal about their own support needs? How can these needs be better addressed?

The Care Programme Approach

The CPA was devised to ensure service users are supported, engaged and robustly managed by mental health services (Warner, 2005). It is also a framework for essential communication between agencies enabling coordinated care planning, particularly in terms of managing risk. The approach was introduced to provide a framework for effective mental health care for people with severe mental health problems (Department of Health, 1990). It has been periodically reviewed (DH, 2008; DH, 2001) and has evolved in a number of ways. Today, it is the standard patient management approach in mental health generally.

Law and policy on carers

In recent decades, various laws (Box 1) and policy documents have stressed the importance of the role of carers in looking after people with mental health problems or learning disabilities. Their contribution to society was formally acknowledged in the Carers (Recognition and Services) Act 1995, while the national service framework for mental health (DH, 1999) highlighted...
that people who look after users of adult mental health services have a right to support of a recognised national standard. The Carers and Disabled Children Act 2000 states that all carers aged 16 or over who provide regular and substantial care for someone aged 18 or over have the right to a needs assessment.

Since the role was developed, responsibility for offering needs assessments to carers lies with care coordinators, who may complete the assessment themselves or signpost carers to another service. The Carers [Equal Opportunities] Act 2004 gave carers the right to an assessment of their needs as a carer.

More recently, the Equality Act 2010 highlighted the rights of carers at work, stipulating that employers cannot discriminate against them because of the commitments of their caring role. Finally, the Care Act 2014 once more stressed the key role played by carers and the importance of addressing their needs, exploring what authorities and society can do to better support them, making a carers needs assessment a statutory duty.

Why this study?
Bradford District Care Foundation Trust is a mental health and primary care trust providing mental health, community and learning disability services to Bradford and the surrounding area. The trust receives comments from service users and carers via feedback forms or questionnaires, as well as formal complaints. However, no formal analysis of family carers’ views and experiences of the CPA has ever been carried out.

I felt it was appropriate and timely to evaluate the CPA process from the perspective of carers following the publication of the Care Act 2014. I decided to conduct a study exploring the lived experiences of carers looking after dependants who were managed with the CPA at the trust.

A majority of participants did not know what to do or who to contact in a mental health crisis.

Literature review
A review of the literature back to 1992 was undertaken using the keywords ‘mental health’, ‘carers’, ‘evaluation’, ‘Care Programme Approach’, ‘CPA’ and ‘case management’. The Cochrane and Emerald databases were searched to identify any papers on carers’ experiences of the CPA published in the UK; other countries were excluded because the CPA is unique to this country. Few publications were identified that focused solely on carers’ views on the CPA. In a further search, carried out on the EBSCO platform (which includes the PsycINFO, CINAHL, MEDLINE, Embase and Campbell databases), as well as on Google Scholar, most papers identified were on service users’ evaluation of mental health care provision in general.

Findings from a previous audit
The most similar to the present research was a large-scale audit carried out at a training hospital (Allen, 1998), which involved one-to-one and group interviews with carers. Most of the carers who participated had never heard of the CPA and the few who did know about it had received no explanation of the CPA process. Most did not know whether or not their dependant was receiving care based on the CPA.

A majority of participants did not know what to do or who to contact in a crisis, particularly outside working hours. There were concerns about inadequate information given to carers on diagnosis, treatment and the CPA process, and participants described feeling isolated, frustrated and confused.

Confidentiality was mentioned as a barrier in communication: often, clinical staff did not feel comfortable having a discussion with a carer because they feared breaching patient confidentiality. Allen further reported that carers often felt intimidated at CPA meetings because of the formality of the procedures and the large number of professionals present (Allen, 1998).

Findings from other studies
Concurring with Allen’s findings, a recurrent theme in the literature was the lack of information about care plans, particularly on diagnosis and treatment. This was highlighted by Carpenter and Sharaini (1996), who stressed the importance of involving service users and carers in the development of individual care plans. Lloyd and Carson (2005) identified that carers need information that is relevant, accessible and understandable by people with different levels of comprehension.

Carpenter et al (2004) found that a common complaint from carers was the use of jargon in care plans and at CPA meetings. This chimes with our experience at Bradford District Care Foundation Trust, where carers and relatives often complain about the jargon used in the CPA process, with nurses being the worst culprits. Carers have reported that the language used made them feel more isolated and confused.

Aims and methodology
The purpose of the study was to elicit carers’ ‘real-world’ views of the CPA. It examined how carers were involved, to what extent they felt supported and what relationships they had with care coordinators. It also sought to identify potential improvements and barriers to better supporting carers. A deep analysis of carers’ experiences would inform the trust on any service improvements required.

A pragmatic qualitative approach was used (Creswell, 2012), as it would allow the investigation of new knowledge in this area and provide insight into carers’ perceptions. Qualitative methods were used for interviewing carers from different
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backgrounds to understand their experience of the CPA.

Participants
Purposive, non-probability sampling was used to recruit participants among carers of adult patients (aged 18-65 years) at the trust. This age group was chosen because it is the largest in terms of the numbers of complaints received and serious untoward incidents occurring. Ten potential participants were approached via different networks, including informal carer support groups and community psychiatric nurses, and eight agreed to participate.

Three of the eight participants were of South-East-Asian origin, two of whom were male; the remainder were white British females; this sample was representative of the demographic make-up of the trust’s catchment area. The interviews began in the summer of 2014 and were completed by spring 2015; each took approximately one hour.

Methods
In-depth, semi-supported interviews were conducted with the eight carers; this form of interview has a number of advantages, which are listed in Box 2. I was careful not to lead participants when they were telling their story (Dey, 1993), as this could have influenced their responses and impinged on the study. Both during the interviews and after when reflecting, I took field notes (Yeh and Inman, 2007) on participants’ emotions, expressions and behaviours – adding another layer of information to the data (Polit and Beck, 2003).

A thematic analysis was carried out using Burnard’s (1991) 14-stage method (Box 3). This involves data immersion, open coding, and the creation, reduction and refinement of categories, with the aim of encapsulating themes and subthemes emerging from the data.

Findings
Six of the eight participants reported having a negative experience of the CPA; the other two reported having a positive experience; in their view this was largely due to their relationship with the care coordinator and the fact that they felt listened to, included and valued.

Some of the themes and subthemes that emerged were consistent with the wider literature, while others were new. The fact that participants’ accounts revealed similar experiences to those reported in the literature adds credibility to the findings. The core themes are described below.

Box 2. Advantages of semi-supported interviews
- Participants are enabled to express their feelings and recount their experiences in a safe and structured environment
- Researchers can obtain richer data than through other methods such as questionnaires, which limit the quantity and quality of information gathered
- They gain a higher level of engagement from participants than other methods because interviews require less work and can be arranged at a convenient time and location for carers, who often have little free time

Box 3. Burnard’s 14-stage analysis
1. Note taking
2. Immersion in data
3. Open coding
4 and 5. Reduction and refinement
6. Checking
7 and 8. Re-reading and categorisation
9 and 10. Rearranging data
11. Informant checking
12-14. Preparing to write, report writing, linking to literature

Source: Adapted from Burnard (1991)

Poor communication
Good communication is crucial to ensure carers have a positive experience, but was far from universally achieved. The two carers who reported a positive experience felt this was largely due to the individual qualities of the care coordinator, notably an open and transparent communication style. They explained that it had taken them a few years to reach that stage and that they had to complain and campaign for their voice to be heard.

The six carers who reported a negative experience felt they were not valued or included as carers and felt depersonalised as a result; for example, their importance to the patient they cared for was not acknowledged. They hinted that not all care coordinators followed the CPA framework in terms of involving carers. One said: “I just felt totally excluded. I didn’t know what the subject matter was about and what the problems were, and I didn’t know anything about the solution.”

Participants were not always given advice about treatments or notified of a change of medication, whether at CPA meetings or generally as the patient’s main carer, and felt this lack of communication was linked to the relationship they had with the care coordinator or consultant psychiatrist. One participant said: “I was not told about the changes in his medication [despite the fact that] I was the one collecting his prescription and making sure he took his medication.”

This was frustrating and demoralising; as one participant said: “It’s like we don’t exist.”

There was a general lack of awareness and understanding of the CPA process among participants, and it was obvious from the data that not having clear information was anxiety-provoking for them.

Poor risk management
It emerged from the interviews that professionals did not always consider the risks to carers associated with their caring role; for example, there were occasional risks of violence towards carers should treatment of the person they cared for not be managed appropriately, or as part of their illness. This, coupled with the poor sharing of information described above, meant risks to carers were increased. It was also clear that safeguarding, whether of carers or patients, was not always considered.

Patient confidentiality was cited as the main reason for not sharing information. This is in line with the literature, where professionals invoking patient confidentiality as a reason for not sharing information with carers is a recurrent theme. Proactive risk management and good sharing of information was linked with positive relationships between carers and care coordinators.

Carers’ health and wellbeing
The issue of carers’ own health and wellbeing came up in all eight interviews. Most participants had some long-term health problems, which seemed to have developed during their time as carers. This highlights the impact caring can have on a person’s wellbeing, the need for car coordinators to be aware of carers’ support needs and the importance of conducting needs assessments. In the literature, carers often explain that they are unable to attend appointments for their own health because they cannot take time off their caring responsibilities.
Cultural barriers

Some carers mentioned cultural norms of caring duties and therefore, did not even recognise themselves as carers. This was how some participants felt about themselves – in their own eyes, they were not carers but simply relatives doing their duty. These perceptions were a barrier to accessing support, causing carers to become even more isolated.

Lessons to be learned

Recognising carers, emphasising their contribution and involving them in the CPA process is crucial. Carers need to be recognised and involved from the point of referral, as well as during assessment and in the planning of care. This will ensure that the CPA process is a positive experience for them and that their needs are met so they can fulfil their caring role more effectively.

Care coordinators must be encouraged, through training and team briefings, to consider carers’ needs from the outset, assess their needs and put in place personalised support plans. These principles are taught in CPA training, but the message may not be getting across to practice as well as it should (Simpson, 1999).

Not every service user will have a carer, and not all carers will identify themselves as such. This is particularly important to remember when working with people from minority cultural backgrounds and communities, as cultural issues may prevent carers from seeking support, thus compounding their isolation (Leong and Lau, 2001). Care coordinators should be aware of this when assessing carers’ needs and address any barrier appropriately.

Changing practice

The findings of the study have led to the formulation of recommendations for practice improvements at a local level. Some of the findings, particularly the importance of proactive risk management, have been incorporated in the trust’s mandatory training on the CPA and clinical risk, so care coordinators can learn from them and adapt their practice accordingly.

The findings have been disseminated at governance level and to carers’ groups, and team managers are now cascading them to clinical level in an effort to bring about the necessary changes in practice.

Bradford District Care Foundation Trust also manages primary care services, and the district nursing service used the study findings to explore how it deals with carers, particularly those looking after patients with long-term conditions or receiving end-of-life care. Some of the findings have been included in the trust’s in-house training for district nurses. This shows that the findings are not specific to mental health and are therefore potentially transferable to other settings or areas.

The trust is currently devising a carer rolecard based on the study findings for its care coordinators, which will act as a guide and aide-memoire.

Recommendations

Only carers were interviewed in this study; it could be helpful to eliciting the views of care coordinators as well, as this could help us understand why some professionals are still not involving carers fully in the CPA process. It could also be helpful for the trust to carry out an annual carer survey to gain feedback from carers, monitor progress and adjust its approach accordingly. Focus groups may be beneficial as a means of gathering this qualitative data (Morgan, 1997). Further recommendations for improving practice are listed in Box 4.

Conclusion

The CPA process needs to be explained from the outset, both verbally and through information leaflets, so that carers know what to expect. Although this is happening in some areas it is not universal. Discussions with team leaders need to take place to ensure this becomes part of the normal protocol.

A culture shift is required so that the carer is recognised as the most important person to the service user from the start of the CPA process. Staff need to acknowledge that carers are central to patient care, work in partnership with care coordinators, and put in place personalised risk management plans.

In 2013, the research proposal that led to the study reported in this article obtained an award from the Care Programme Approach Association (now the Care Coordination Association: www cpaa org uk) in the category ‘Excellence in monitoring and evaluating the CPA process’.

References


