"It doesn't mean I'm useless"

How do young people experiencing psychosis contribute to their families and why are their contributions sometimes overlooked?

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'It doesn't mean I'm useless': How do young people experiencing psychosis contribute to their families and why are contributions sometimes overlooked?

Abstract

Purpose: Psychosis is often seen as a "burden" on families. and affected individuals frequently hold a negative view of themselves. This study explored the ways in which young adults who have experienced first episode psychosis (FEP) make a positive contribution within their families.

Methods: Fifteen participants (seven young people with experience of psychosis and eight relatives) were interviewed separately. Their accounts were analysed using grounded theory methodology (Charmaz, 2006).

Results: For many individuals, their experience had led to a catastrophic redefinition of their identity. However, they continued to contribute significantly both within their families and within their wider communities. The redefinition of identity sometimes appeared to create a 'perceptual filter' whereby both the person themselves and family members overlooked or minimised their contribution, focusing instead on being alert to signs of psychosis or illness.

Conclusions: Shame and a focus on symptoms rather than achievements and contributions can significantly limit opportunities, expectations, and movement beyond an illness identity. It is important for clinicians to be aware of this and to help young people and their families to notice and value positive contribution, and so promote recovery, well-being and post-traumatic growth.

Introduction

For the majority of those who experience psychosis, the first episode ("first-episode psychosis" or FEP) occurs in adolescence or "emerging adulthood" (World Health Organisation, 2004). This period often represents a time of instability and identity formation when the young person explores possible future roles and lifestyles. Challenges and opportunities encountered in the course of such critical transitions may shape life goals and aspirations, and the person's enduring sense of self (Little, Philips, & Salmela-Aro, 2007).

A psychotic episode is often a major, traumatic life event both for the individual him/herself and his/her family, leading to both parties actively re-orienting goals and expectancies (Slade, 2009). The way that individuals, families and society make sense of and respond to experiences of psychosis may have significant consequences for the person's forming identity and future wellbeing.

A number of authors (e.g. Birchwood, Fowler, & Jackson, 2000) have suggested that by framing psychosis as "severe and enduring illness", services have historically overlooked the possibility that a first episode may constitute a critical period in determining future outcomes. Birchwood and colleagues recommend that services should focus on preventing secondary disability or a future "spoilt identity" (Goffman, 1990).

A member being diagnosed with "serious mental illness" has been described as a "pivotal, catastrophic and cumulative" stress for a family (Lukens, Thorning, & Lohrer, 2004, p. 489). There is a large literature on 'carer burden' (e.g. Kuipers &

Bebbington, 2005). Notwithstanding the undoubted strains of caring (Cooke, 2017) it is possible that a focus on "burden" may contribute to poor self-image amongst people who have experienced psychosis (Ahmed & Boisvert, 2006). It may also hinder the development of an evidence base regarding their strengths and contributions.

A growing body of research suggests that there can be positive as well as negative aspects to psychotic experiences. For example, some people view their crisis as transformative (Cooke & Brett, submitted) and there is increasing interest in the idea of post-traumatic growth (Zoellner & Maerker, 2006). Individuals with a diagnosis of schizophrenia have been shown to make a positive contribution to their families (see Coldwell, Meddings, & Camic, 2010). A contribution is defined as any action which has a positive impact on the family, be it practical (e.g. childcare) or emotional (e.g. support). However, the available literature has a number of limitations. Few studies include a service user perspective and only one has undertaken qualitative exploration of the nature of contributions (Coldwell et al., 2010). Participants in the latter study had ongoing difficulties, and its relevance to individuals who are experiencing psychosis for the first (and perhaps only) time is unclear. It is possible that such individuals make an even greater contribution. This also seems a critical period to study given that identities and future trajectories are being shaped (NIMHE, 2004). The development of an evidence base relating to positive contributions may help counter negative stereotypes and protect young people's developing self-concept and self-esteem (Cooke, 2017).

The aims of the current grounded theory study were therefore to:

1) Explore individuals' and their families' perceptions of the extent to which positive contributions are lost or preserved during, and following, a first psychotic crisis

2) Explore the processes by which positive contributions are acknowledged, maintained and increased

3) Develop an exploratory model explaining the relationships between these factors.

Methodology

Participants

Fifteen participants were interviewed. Participants had either experienced FEP ("individuals"/ "young people") or were a family member or partner of someone who had ("relatives") (Table 1). Individuals were recruited through Early Intervention in Psychosis (EIP) services in two NHS Trusts and had used those services for between 6 and 24 months. Services considered young people to be stable, although most were experiencing ongoing symptoms. All had had at least one hospital admission and/or been subject to compulsory treatment. In order to preserve anonymity, quotations will indicate only whether the participant was an individual or relative, and references to individuals will use the female gender. Table 1 summarises participant characteristics.

Table 1: Participant Characteristics

Name*	Age	Gender	Status	Accommodation	Employment	Diagnosis	Frequency of contact
Margie ***	16-20	Female	Individual	Living with partner	Student	Depression with Psychosis	Several times a day
Caroline ***	16-20	Female	Individual	Living in family Home, with Susie and David	Volunteer	PTSD with Psychosis	Several times a day
Natalie ***	16-20	Female	Individual	Living with partner	Student	PTSD with Psychosis	Several times a day
Janet ***	26-30	Female	Individual	Living independently	Unemployed	Psychosis	At least once a day
Hannah**	16-20	Female	Individual	Living in family Home	Part-time	Bi-polar with psychosis	Several times a day
Susan ***	21-25	Female	Individual	Living with partner	Full-time and Student	Psychosis	At least once a day
Simon	16-20	Male	Individual	Living in family Home with Ruth	unemployed	Schizophrenia	Several times a day
Sally	21-25	Female	Margie's Partner	Living with partner	NA	NA	Several times a day
Melissa	46-50	Female	Natalie's Mother	Not living with Natalie	NA	NA	Several times a day
Susie	46-50	Female	Caroline's Mother	Living in family Home with Caroline	NA	NA	Several times a day
David	36-40	Male	Caroline's father	Living in family Home with Caroline	NA	NA	Several times a day
Robin	46-50	Female	Janet's Mother	Not living with Janet	NA	NA	At least once a day
Elaine	56-60	Female	Susan's Mother	Not living with Susan	NA	NA	At least once a day
Ray	61-65	Male	Susan's Father	Not living with Susan	NA	NA	At least once a week
Ruth	36-40	Female	Simon's Mother	Living in family Home with Simon	NA	NA	Several times a day

* Pseudonyms   **Singleton   *** Experienced positive symptoms in the month before interview

Procedure

Service users who met study criteria were approached by a member of EIP staff. Interested participants gave consent for the staff member to pass on their contact details. Participants gave written consent.

Data were collected through semi-structured interviews of 40 to 90 minutes' duration which were recorded and transcribed.

Analysis

The data were analysed using standard procedures for Grounded Theory (GT) (Charmaz, 2006). Reflexive diaries, memos and auditing were used to ensure the quality and reliability of the analysis. (These are available, together with the interview schedules and further details of methodology and analysis in Allman, 2011). Through the use of "bracketing", the research team periodically reviewed how pre-existing beliefs and commitments might be influencing the emerging model (Willig, 2008). Credibility of the findings was evaluated using Yardley's (2000) guidelines.

Epistemological Position

As is common in Grounded Theory studies (Charmaz, 2006), the epistemological position adopted in the study was one of critical realism (Bhaskar, 2013). This stance acknowledges that the statements made by the participants are just that, statements, and can only reflect participants' perceptions rather than being a direct index of the processes they are describing. However, unlike its more radical cousin social constructionism, critical realism sees these statements as often containing valuable information about the 'real world' - the phenomena being described - albeit seen though a particular lens. Accordingly, the assumption here is that participant statements do reflect, albeit imperfectly, the nature of the young people's *actual* contribution, as well as participant beliefs and assumptions. The interview method has the advantage not only of being more practical than sending researchers directly into people's homes, but also of capturing people's reflections on, as well their accounts of, events.

Results

Summary

All participants confirmed that the young people made extensive positive contributions to their families. However, such acts frequently appeared to go unnoticed. The opportunity for contribution appeared to be shaped by individuals' self-concept and also the family's view of them, particularly of their ability to manage difficulties. However, those individuals who contributed most significantly were not necessarily seen as more able to cope. The extent to which contributions were noticed and valued appeared to depend largely on the context, on the relationships between the individuals concerned, and on the extent to which the person viewed him/herself, or the family viewed him/her through what might be called a "perceptual filter" whereby the psychosis came to dominate their identity.

These processes are summarised in Table 2 and will now be explained in more detail, with examples.

Table 2: Themes in young people's and relatives' accounts of their contributions to their families following first episode psychosis

Overarching themes	Themes
Contribution	Practical support
	Emotional support
	Reciprocal exchange
	Family & personal enhancement
Changed identity	Psychosis-as-self
	Acting normal
	Personal growth
Managing difficulties & expectations	Managing difficulties
	Perceived ability to cope
Noticing &valuing	Perceptual filter
	Relationships and context

Contribution

Most young people and their relatives considered them to be contributing as much as or more than their peers:

> *I think already she does far more than most teenagers* (Relative)

> *She's still a good role model for her sister…a better person than a lot of teenagers that don't have psychosis* (Relative)

> *She'll do the ironing, or clear up…her brother wouldn't do, but she would without being asked.* (Relative)

While contributions reduced during crises, they rarely disappeared completely. Contributions appeared to take four main forms:

Practical Support

Individuals were described as contributing in numerous practical ways including care-giving, financial support, housework, cooking and sharing their particular skills.

> *I do the housework with my mum, every day…I sometimes cook dinner…I help around the house a lot and do a lot of sewing and craft things.* (Individual)

Emotional support

Most interviews highlighted the emotional support that individuals gave to other family members:

> *She's somebody who I can trust, who I can rely on, who I can talk to… if I feel down myself she's there…She goes to a lot of effort to let you know that you, yourself, are valued and loved.* (Relative)

Reciprocal exchange

In most cases help and support was mutual. Three of the young people were themselves also long-term carers.

> *I've always got a feeling that they can rely on me* (Individual)

Personal and Family enhancement

Whist all families had found the experience stressful, all felt they had also benefited. Examples included becoming closer as a family, discovering strengths, gaining knowledge, empathy, skills and self-worth, recognising the need to make changes and coming to value and appreciate life more.

> *Other people who haven't been through something quite as severe as this, don't quite know how they would cope with it. But we know.* (Relative)

Changed identity

Most participants felt that their experiences had changed the way the young person viewed and felt about themselves. These changes fell into three main categories, labelled respectively as "psychosis-as-self", "acting normal" and "personal growth".

Psychosis-as-self

Even though things often returned much to normal after a crisis, the experience and being labelled "psychotic" often appeared to lead to a catastrophic redefinition of the young person's identity. Many described feeling defective, abnormal and shameful, and some feared that they might become violent. This appeared to be related to social stereotypes of psychosis (Cooke, 2008):

> *The name doesn't help… when I got told, I just thought I'm a psycho… you just think of someone that goes killing people and…does crazy things* (Individual)

The extent to which this redefinition of identity was experienced as catastrophic appeared to be related to the degree of prejudice or discrimination that people experienced or expected from others. Both individuals and relatives indicated that they frequently experienced discrimination, and that this limited potential opportunities to contribute within their communities.

> *My Manager…said in front of me "Don't ask [name] because she's crazy" and then no one asked me my opinion.* (Individual, who shortly afterwards left her job)

Stigma and shame sometimes appeared to overshadow contribution and minimise any positive effect it might have on well-being and identity. Even where individuals knew they made a positive contribution, they often held a negative view of themselves, and social stereotypes also appeared to affect the way their loved ones viewed them.

> *Just because some people are ill, it doesn't mean that they're useless…but then I would be like "…you're weird".* (Individual)

Acting normal

Fear of discrimination or of being judged or stereotyped led to enormous pressure to appear "normal". Some young people hid their experiences or avoided showing any strong emotion. This sense of needing to put on a front often reinforced individuals' sense of difference. One participant used the metaphor of "coming out":

> *I think it's more detrimental to a person to hide who they are because then you get really confused about who you actually are. Cause there's the person you're being, and the person you are…do the actions make the person? …If you don't know who you are, they're* [others] *not going to know.* (Individual)

Personal growth

Despite these challenges, all but one of the interviewees felt that the individual had grown and developed through their experience. Participants described increased maturity, empathy, responsibility, strength, resilience, a better sense of humour and a better appreciation of life. Whilst these were sometimes attributed to the normal course of maturation, many participants felt that the experience of psychosis had been highly significant.

If I can get through that and having them horrible experiences every day, all day, then I can do anything. (Individual)

Managing Difficulties and Expectations

The level of contribution was influenced not only by the nature and extent of the person's ongoing difficulties but by their own and others' expectations of their ability to cope. Whilst there was an increase over time in both expected and actual contributions, this did not automatically alter how the individual was viewed by themselves or others.

Managing difficulties

Whilst young people who were still experiencing intense symptoms often found it harder to contribute to family life, this changed as they found ways to manage their difficulties.

> *The voices weren't controlling me enough to hide away, so I was able to go look after my Nan.* (Individual)

Perceived ability to cope

Individuals and relatives often feared that particular activities might be too stressful for the young person. Especially where he/she had attempted suicide or relatives had feared "losing" them to madness, both parties tended to err on the side of caution.

Participants described the tension between over-protectiveness and expecting too much. Two relatives used the analogy of "giving some rope":

> *I gave her a bit of rope, because I had to… I couldn't have wrapped her up in cotton wool for the rest of her life.* (Relative)

Noticing and Valuing

Interestingly, it was often only in the course of the interviews, as people described the various contributions that the young person made, that it became clear to them just how much he or she did. At the beginning, many young people and relatives had stated that they were contributing little. It appeared that even when contribution was substantial, it often went unnoticed and therefore largely unvalued.

Perceptual Filter

For some participants – both young people and relatives – there appeared to be a kind of perceptual filter, which led them to focus on the support received rather than the contribution made by the young person. Participants sometimes appeared to take acts of contribution for granted rather than viewing them as such. For example, one young person was a carer for an elderly relative, but neither they nor their relatives mentioned this when asked directly about their contributions. At the extreme, some individuals considered that they contributed nothing at all.

> *I don't do anything, my mum just does everything for me, I just take.*
> (Individual who was a carer for a physically disabled sibling)

This often appeared to relate to the degree to which, for the speaker, the individual's identity had been "catastrophically redefined".

> *When I read your form…I was really worried because it said what positive effects does [individual] have? And I thought "Oh my God, she's got psychosis…I don't know that there is anything positive"* (Relative of above individual)

Some young people felt that aspects of contribution and growth had arisen directly out of the psychotic experiences themselves. However, the pain that the crisis had caused them and their families often made it hard to acknowledge the positives:

> *… Whenever I think of it, I just think how it's ruined my life... So it's really hard to think of the good stuff... I know there is, but it's really hard even saying it because then I feel like I'm betraying myself because I've just come through a year of hell and then I'm saying "oh there's good stuff," and there shouldn't be. (*Individual)

Relationships and context

Changes in relationships or context were important in creating opportunities for, or highlighting, contribution:

> *I watched her with the adults at this centre* [charity where the individual was volunteering]*, she was... very mature with them, very well organised, very caring and she seems to be able to sort of change herself...within a different environment.* (Relative)

Even when there was a clear awareness of acts of contribution, the value attributed to such acts was dependent on context. For example, if participants were focused on a particular goal (e.g. being symptom-free or gaining employment), they tended only to value contributions which related to that. Another important aspect of context was simply the opportunity to reflect on contributions and on progress more generally. Some participants commented that the interviews themselves had been helpful in this regard:

> *Just, talking about it… with you…shows me…how far we've come... And this is the first time I've complimented myself, tonight, and I was just like "wow".* (Individual)

Discussion

The current study is the first to focus on the positive contribution made to their families by young people who have experienced psychosis. It is a small, qualitative study and so any conclusions can of course only be tentative. Nevertheless, in these families at least, it appeared that individuals with FEP were able to, and regularly did, make a significant contribution within not only their families but also their communities. Indeed, many were described as contributing equivalently to, or more than, peers. However, it appeared that even when contribution was substantial, it often went unnoticed and therefore largely unvalued. This may constitute a self-fulfilling prophecy: the failure to notice or reinforce contribution may lead over time to its diminution. A "perceptual filter" often appeared to be in operation whereby contribution went unnoticed because attention was focused elsewhere, for example on symptoms or on catastrophic fears of losing oneself or one's loved one to madness and a "mental patient" identity. This is consistent with the findings of Markowitz, Angell and Greenberg (2011) who suggested that stigmatised self-appraisal in individuals diagnosed with schizophrenia may be related to poorer long-term outcomes.

Expectations appeared to play a key role in determining whether contributions were noticed, reflecting Raune, Kuipers and Bebbington's (2005) distinction between objective and subjective burden. Expectations seemed to act as a filter, focusing attention on problems and risking keeping families stuck in an "illness ideology" (Maddux, 2008).

Significantly, the current findings contrast with Charmaz' (2002) findings relating to in self-concept in severe physical illness, which suggested that it does not change immediately upon diagnosis but rather gradually through iterative feedback. In

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contrast, both individuals and family members indicated that being diagnosed with psychosis had led to an *immediate* and, for many, *catastrophic* change in self-concept - and in how others saw them - changing their identity to that of a 'mental patient' (Cooke, 2008). Significantly, it appears that the strength of this new identity can create a perceptual filter or "reverse-halo effect" (Nisbett & Wilson, 1977), which makes it resistant to being changed by subsequent information. While all individuals in the current study appeared to be engaged in regular acts of contribution, it was interesting that at the start of the interviews, many young people and relatives had begun by stating that the individual was doing little to support his or her family. It was only as the interviews progressed, and as they named the various things that they young person was doing, that they realised that this was not the case.

Clinical Implications

1. *The damaging effects of an "illness identity*"

Tracy Emin's work "My Bed" clearly exemplifies that the perceived value of an object depends to a large extent on its context (see e.g. Cherry, 2002). In a particular context, a detritus-covered bed is transformed from an object of shame to high art. Duchamp's 'Fountain' does the same with a urinal (see e.g. Mundy, 2016). Conversely, the challenging nature of psychotic experiences, combined with stigma of the label, can create a context which overshadows any other expressions of identity (Lally, 1989). If the self becomes synonymous with psychosis, acts which would normally be ascribed value may be viewed as irrelevant, and may therefore make little difference to how the individual is viewed or views him/herself. This may be one of the processes by which a "spoiled identity" (Goffman, 1990) is maintained.

In addition to being viewed as irrelevant, positive acts of contribution may be attributed to external factors rather than to the individual. For example, in the current

study many individuals and relatives attributed an individual's contribution to changes in medication/therapy/service input. These may of course have played an important role for some, but it is the way that participants' accounts often appeared to privilege them that is of interest here. An ironic process appeared to occur whereby increased contribution, when framed in relation to improved management of "symptoms", located agency outside the individual and confirmed his or her identity as a "psychiatric patient"(Maddux, 2008).

2. *The importance of asking about positive contributions*

Both the current findings and those of Coldwell et al (2010) indicate that simply asking about positive contribution may help to counteract this perceptual filter. This suggests that it is important that workers routinely ask about it.

Recognition of people's contribution might help reduce symptoms

Several studies have suggested that the more negative one's sense of self, the more negative the content of hallucinations (e.g. Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001). Additionally, Garety et al (2001) suggest that the strength with which psychotic beliefs are held is related to the extent to which they fit with the person's self-concept. Recognising the value and worth of acts of contribution may therefore not only be important in its own right but may lead to symptomatic improvement if the individual starts to relate to himself or herself more positively.

3. *Recognition of personal agency and the potential for recovery can aid post-traumatic growth after crises*

There is growing interest in the idea that psychotic crises, whilst distressing, can also be "transformational" in the sense of leading to growth and development (Cooke & Brett, submitted). In general, positive change following traumatic events is heavily

influenced by the degree of control that the person perceived themselves to have had in the traumatic situation, even if this control was illusory (Zoellner & Maercker, 2006). Therefore, neglecting personal resilience and locating agency outside the individual (e.g. in family 'carers' [Murray, 2014] or services) may reduce the potential for such growth (Tedeschi & Calhoun, 2004) following psychotic crises.

Modifying perceptions of agency may also modify the perceived demands of care-giving. The cognitive-mediational stress theory (Lazarus & Folkman, 1984) suggests that the affective response to a demand is based on an appraisal of the nature of the demand in relation to one's belief that one can meet it ('self-efficacy'). If relatives perceive themselves as wholly responsible for their loved one's mental health, they are more likely to appraise this situation as being beyond their capacity. Services could perhaps be more cautious in ascribing the term 'carer' in this regard (Slade, 2009). Conversely, increasing awareness of a loved one's agency and abilities may decrease the perceived emotional strain. Similarly, access to support and materials (e.g. Cooke, 2017) which stress the possibilities for recovery and growth could make a significant difference both for people who have experienced a psychotic episode and for their families.

Limitations

A number of factors limit the generalisability of this study. Firstly, the sample was small and relatively homogeneous: all participants were White British, most were female and all were in regular contact with family or partners. Their experiences may not represent those of, for example, individuals from other ethnic backgrounds or who live alone. It is also possible that the sample was self-selected in the sense that individuals who make less frequent contributions, or their families, might have been less motivated to take part. However, notably, prior to interview four of the fifteen

participants expressly stated that either they or their family member did not contribute at all. Practical constraints prevented theoretical sampling in this regard (i.e. specifically interviewing individuals who differed in these respects) and this would be interesting to explore in future studies.

Future research

The findings suggest it would be useful to explore the relationship between contribution and recovery in FEP. Research with participants from different backgrounds or less family contact would also be useful, together with clinician beliefs about positive contribution. It is possible that the difficulties experienced in recruitment were partly the result of such beliefs. Services frequently reported difficulty identifying possible participants because care-coordinators viewed their clients as not contributing to their families. This is significant as whilst hope is known to be important in recovery (Leamy et al, 2011) services may be communicating a message of hopelessness. Finally, longitudinal research would help to clarify the processes involved and the direction of causality.

Conclusion

The results suggest that while individuals with FEP can and regularly do contribute to their families, such contributions may not always be noticed or valued. The catastrophic redefinition of identity that occurs upon being labelled psychotic, together with the effects on both service users and their families of current social narratives about psychosis, appears to direct attention away from the positive contributions which individuals make. This in turn may reduce opportunities for them to occur and be incorporated into the individual's identity. If both services and families are careful to notice and value contribution, this may reduce stress and enhance wellbeing for all concerned.

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