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TITLE PAGE FOR MAJOR RESEARCH PROJECT

Justin J.P. Allman BA. Hons Psych., BA. Phil., PGDip Stats, PhD

How individuals with first-episode psychosis positively contribute
to their families. A grounded theory analysis

Section A.: Review of the Literature
5500 Words (plus 41 additional words)

Section B: Empirical Paper
Word Count: 7999 (plus 6 additional words)

Section C: Critical Appraisal
2000

Overall Word Count
15499 (plus 47 additional words)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

NOVEMBER 2011

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

DECLARATION FOR MAJOR RESEARCH PROJECT

Candidate name (PRINTED)

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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STATEMENT 2

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Acknowledgements

I would like to thank my supervisors, Anne Cooke, and Becky Whitfield, for their support, encouragement and support with the project

A special thanks to all the people who took part in the study, whose openness, generosity and hope made the project an experience beyond research.

I would like to thank my family for their continued support and understanding during the long dark night of my continued academia. No more after this I promise. Most of all I would like to thank Michelle, for her kindness, her clarity, her wisdom and for her heart that has more love than is sensible. You are my starshine and moonlight.

Summary of the MRP portfolio

Section A consists of a review of the literature relating to positive contribution to families in first-episode psychosis. It highlights potential gaps in the research and possible avenues for future research.

Section B presents the findings of a grounded theory study which aimed to explore whether individuals who have experienced first-episode psychosis positively contribute to their families.

Section C offers a focused evaluation of the research study in section B. Topics of evaluation included reflections on the research process, learning experiences, further clinical implications and possible future research.

Section D consists of appendices containing relevant supporting material.

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SECTION A. Review of the Literature

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Do individuals with experiences of psychosis positively contribute
to their families?

Section A: Review of the literature
Word Count: 5500 (plus 41 additional words)

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Aim. This review aimed to critically evaluate the literature which has addressed how and in what ways individuals who have experienced psychotic symptoms positively contribute to their families. Additionally, the review aimed to highlight potential gaps and suggested avenues for future research particularly with reference to the early stages of psychosis.

Method. COCHRANE database of systematic reviews, PsycINFO, Wiley Online Library, Sage Journals online, ScienceDirect, and Web of Knowledge were searched for peer-reviewed publications. Further searches were carried out on ‘Google Scholar’ and ‘Google Books’ in addition to hand searching of bibliographies.

Results. The evidence suggests that while positive contribution is a relevant and relatively unexplored area of research, there is a clear need to establish a firmer theoretical foundation for the occurrence of acts of contribution in individuals and families who have been impacted by first-episode psychosis.

Conclusion. There is a clear need to establish how individuals and family members who have been impacted by first-episode psychosis view positive contribution, what factors promote or hinder these processes and whether acts of contribution are lost or subsumed in the early stages of psychotic experiences.

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Introduction

This review will critically evaluate relevant research in the emerging field of positive contribution following psychotic symptomatology and how this relates to current conceptualisations of first episode psychosis (FEP). The review starts with a description of psychosis, the relationship between psychosis and the emerging self in FEP, before addressing the impact on the family and the relationship to burden. The review will then focus on the evaluation of current literature within the field of contribution before considering the implications for future research and clinical psychology.

Psychosis

Definition and prevalence

“Psychosis simply means... a type of problem in which the patient appears to be, at least to some degree, out of touch with reality” (Morrison, Renton, French, & Bentall, 2008, p. 4). The experience of being out of touch can involve delusion, hallucination, disorganised thought, speech or behaviour. The term psychosis therefore offers a description of the relevant experiences rather than referencing a particular medical aetiology, e.g. diagnosis of schizophrenia, depression, bi-polar and post-traumatic stress disorder (PTSD) (Fauman, 2002).

First-episode psychosis refers to the first time a person experiences psychotic symptoms, with 80% of individuals experiencing their first-episode between 16 and 30 years of age (World Health Organisation, 2004). One in 200 people are estimated to experience some form of psychotic symptoms in the UK annually (Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2001). There is good evidence for a continuum

of experience, and while it is recognised that clinical populations are “more likely to show distress... high levels of conviction and preoccupation do not distinguish normal from delusional ideas” (Kuipers, 2008, p. 447). Psychotic experiences thereby should no longer be thought of as qualitatively different from normal experience.

Intervention

Intervention aimed at treating psychosis until recently could be construed within two separate but related paradigms: acute crisis; and rehabilitation (Birchwood, Fowler, & Jackson, 2000). Such a conceptualisation explicitly framed psychosis as a long-term and chronic illness, and failed to consider that the early phase of psychosis may constitute a critical period when the trajectory of difficulty and outcome may be fundamentally altered. They suggest that practical implications of the critical period hypothesis centre around “the opportunities it presents for secondary prevention to limit or prevent difficulty and distress” identifying relapse, the cycle of coercive management, suicide, unemployment and social exclusion as “key targets” (Birchwood et al., 2000, p. 57). Birchwood and colleagues suggest changing the emphasis away from crisis intervention and withdrawal to ongoing intervention for a suggested minimum of 3 years. This duration is considered necessary as a means of sustaining and nourishing continued positive change, and would ideally be provided by early intervention services.

While a detailed description of current interventions is beyond the scope of this paper (see Kuipers’ (2008) review), current policy does state that families can often “play an essential part in the treatment and care of their relative” and therefore should be considered an essential part to any interventions offered (National Institute for Health and Clinical Excellence, 2003, 2010). Approximately 1.5 million people care for a relative or friend with a mental health (MH) difficulty in the UK (Rethink, 2003). Given that

having a family member with a ‘serious mental illness’ may be experienced as a “pivotal, catastrophic and cumulative” stress for the family (Lukens, Thorning, & Lohrer, 2004, p. 489), policy and best practice initiatives have advocated that carers have access to services in their own right (Department of Health, 1999; NICE, 2003).

Psychosis in the context of emerging adulthood

The period between 18-25 years of age has been suggested to demarcate a stage of development known as ‘emerging adulthood’ (Arnett, 2004). The period for most represents a time of instability and identity formation, when young people do not take on full adult responsibilities and shy away from various relational and personal commitments in the process of exploring possible future life-styles and roles. It is suggested that before emerging adults are able to “make enduring life commitments (e.g., romantic commitments, career choices) by the end of their 20s, they must first undertake the psychological task of individually forming a stable and viable identity that can guide and sustain these commitments.” (Schwartz, Cote, & Arnett, 2005, p. 202) It is also a time where parents may struggle to let go and acknowledge the developing autonomy of their grown-up children (Kloep & Hendry, 2010). While parents and young adults may hold similar ideas concerning what is necessary for one to become an adult, there may be considerable divergence on the importance placed on certain criteria. E.g. young adults tend to place less importance on risk aversion and compliance than parents do, which can lead to disagreement and conflict (Nelson et al., 2007).

During adolescence and emerging adulthood one of the primary aims is therefore to develop goals and aspirations towards which to direct one’s energy and against which to chart one’s development (Arnett, 2004). According to one life-span model of

motivation, the challenges and opportunities people encounter at critical transitional points in their lives shape the kinds of personal goals they may construct (Little, Philips, & Salmela-Aro, 2007). Goals are therefore shaped by an individual's sense of personal agency in relation to their social environment (family, peer network etc); specifically, they are shaped by what is expected or what others have/are attaining (Salmela-Aro, 2009). This can constitute a self-fulfilling prophecy in individuals' expectations and/or significant others' expectations of the individual may tend to evoke expected responses (LaRossa & Reitzes, 1993).

Psychotic experiences may be more difficult to adapt to as they constitute non-normative or unexpected life demands, beyond that individuals may become a burden on their family. Therefore there may be no readily available societal references or roadmaps which individuals may draw on to re-orientate goals and expectancies, but instead individuals may be forced to actively compensate and develop these goals personally (Wrosch & Freund, 2001). Additionally, family members, friends and loved ones may also not have suitable models readily available to re-orientate their expectations or hopes relative to their loved one, such that a helpful or supportive fit between models may require greater levels of wilful effort to achieve (Harrop & Trower, 2008).

However the increased efficacy of early intervention proposed by Birchwood (2000) may reflect the relative flexibility of identity associated with this stage in development, with processes of familial separation and societal individuation occurring in parallel (Meeus, Iedema, Maassen, & Engels, 2005). Whether

individuals, families and society view the emerging adult from a perspective of burden or value is likely to impact the emerging self.

Psychosis and self

Before being able to understand how psychosis may affect the self, it is pertinent to define what this term means. The self may be conceptualised both as a process and as an object (Gecas, 1982). That is selves are constructed through the processes that an individual engages in (for example, thoughts, feelings, behaviours), with the self-concept (self-as-object) emerging out of the stability or consistency of these processes (Charmaz, 1999). Over time they become enduring meaningful references both to the individual's sense of self (Charmaz, 2002) and how they are viewed by others (Hewitt, 1984).

As experiences (self-as-process actions) are more mutable than the self-concept, individuals constantly relate their actions to an implicit enquiry of, *what does this mean for me* (Mead & Morris, 1967). The 'me' in this case relates to the current definitions of self-concept. The content and boundaries of self are therefore not just predicated in the actions an individual engages in across time but their interpretation of these events in relation to the self and how these may be viewed by others (Hewitt, 1984). Reflexivity or the ability to go back and forth between the self-as-process and self-concept is essential to establishing a sense of agency and meaning in the world. Experiences which do not immediately fit with the current definition of self-concept therefore may: bring about a change in the self-concept; go unnoticed; or can be attributed to situational rather than characterological circumstances (Charmaz, 2002).

The meaning ascribed to an experience has central importance as it is suggested that individuals and families act towards things on the basis of meaning that a thing has for them (Hewitt, 1984; LaRossa & Reitzes, 1993). For example, an individual's response to a dog will differ depending on if it is viewed as a cuddly companion or a vicious beast. The creation of an object through symbolic representation (language), allows individuals to act towards the symbolic object as if it were a real physical thing (Hewitt, 1984). Meaning is therefore not seen as an inherent property in objects/events/actions but is subjectively derived from and modified through social interaction (Mead & Morris, 1967). "Reality rests largely on a social consensus. Language shapes what we know and what we see, as well as what we can say" (Marecek & Hare-Mustin, 2009, p. 76). Assertions or judgements relating to normality/abnormality, goodness/badness, sickness/health etc, are thereby not considered to naturally exist in themselves but are formed or constructed from social and cultural interaction.

The impact of FEP particularly for "relatively young and developmentally immature" individuals has been described as "potentially cataclysmic, causing derailment, truncation, deflection, or paralysis of the person's developmental trajectory" with a "potential to change or alter the persons usual way of construing themselves, the environment, and their future" (Jackson, Edwards, Hulbert, & McGorry, 1999, p. 271). Thus how individuals, families and society make sense of, view and respond to experiences of psychosis may have serious consequences for the person's identity formation and future wellbeing. For example, has an individual experienced psychosis or have they become psychotic? In the latter description the label may occupy the

individual's entire identity, and may hamper the ability to ascribe value to self or action (White, 1987).

The self-as-process actions an individual engages in during or after the experience of psychosis may therefore have a central importance in regards to future conceptualisation of the self-concept. The "illness ideology" within which psychosis is commonly framed "dictates that the focus of our attention should be disorder, dysfunction, and disease rather than health. Thus, it narrows our focus on what is weak and defective about people to the exclusion of what is strong and healthy" (Maddux, 2008, p. 56). Charmaz's (2002) research with chronic physical illness indicated that for some individuals self-concept did not immediately change upon receiving a diagnosis, but gradually altered as the illness or treatment regime forced individuals to recognise that previously taken for granted self-as-process actions had changed or were no longer possible. By failing to separate "problematic attributes, ideas, assumptions, beliefs, habits, attitudes, and lifestyles from the patient's dominant identity" (Tomm, 1989, p. 55), individuals, families and society may incorrectly assume that an individual experiencing psychosis can no longer continue or maintain the roles which previously gave them a sense of wellbeing and success (Slade, 2009). A construct that has an important influence on this is stigma.

Stigma

Stigma is defined as a negative stereotypical belief held about a particular group or condition (Corrigan, 2004; Corrigan & Larson, 2008). Behaviour or experiences which repeatedly defy social norms, particularly if these events become visible to others, can be viewed or labelled as evidence of "mental illness" (Scheff, 1999). The prevalence of stigmatised assumptions within society concerning unusual

'symptomatic' experiences may cause individuals to relate to themselves in a stigmatised manner irrespective of whether a label has actually been assigned (Kroska & Harkness, 2006).

Fear and awareness of the stigmatised label for some is enough to prevent them seeking help and support, to avoid services because continued difficulties are less damning than the label (Wahl, 1999). The process of avoiding the stigma label may constitute a self-fulfilling prophecy, as in order to avoid labelling, one may adopt the coping strategy of the persons so labelled. Adopting strategies such as secrecy, withdrawal, non-disclosure, make it harder to maintain the valued roles which are in opposition to the negative label (Darley & Fazio, 1980).

Internalisation of a stigma identity can usurp or engulf previous notions of identity (Lally, 1989). Thus the subjective perception of devalued and marginalised worth will affect self-esteem even if individuals have not been actively discriminated against by others. "Your label is a reality that; gradually shapes an identity that is hard to shed" (Leete, 1989, p. 199). Through such shaping individuals may lose the freedom to pursue dreams and life goals if their identity becomes synonymous with mental patient (Cooke, 2008). Conversely, acknowledging the hope of reclaiming/maintaining socially valued roles is seen as essential to recovery (May, 2000).

Recovery and post-traumatic growth

Recovery is no longer assumed to be synonymous with symptom remission. Increased service-user consultation has led to an improved governmental understanding that recovery involves empowerment. This is demonstrated in shift in emphasis from the

National Institute for Mental Health in England's (NIMHE, 2004) definition of recovery as "a personal process of overcoming the negative impact of diagnosed mental illness/distress despite its continued presence", to the Care Services Improvement Partnership's (2007) definition of recovery as "the process of regaining active control over one's life" which:

"may involve discovering (or rediscovering) a positive sense of self, accepting and coping with the reality of any ongoing distress or disability, finding meaning in one's experiences, resolving personal, social or relationship issues that may contribute to one's MH difficulties, taking on satisfying and meaningful social roles and calling on formal and/or informal systems of support as needed".

Promoting recovery is one of *The Ten Essential Shared Capabilities* for development of the MH workforce outlined by the Department of Health (2004), which advocates working with service users towards valued lifestyles "within and beyond" the limits of any MH problem.

Several models of recovery have been proposed in the literature (Slade, 2009). McGlashan, Docherty and Siris (1976) distinguished 2 possible recovery styles following a psychotic experience: sealing over and integration. Sealing over is described as an attempt to ignore, minimise or isolate the psychotic experience as it is held as incompatible with one's model of one's self or life. In contrast integration acknowledges continuity between the self before, during and after the psychotic experiences. This can lead to a change in the manner by which the world and self are represented and therefore is associated with adjustment to the experiences (Jackson & Iqbal, 2000). Someone with an integrative recovery style is thereby more likely to

recognise personal agency and responsibility in relation to their experiences, and have more awareness of both pleasurable and negative aspects of the experience. In contrast, having lower expectations of recovery and personal ability predicts poorer outcomes, irrespective of symptom severity (Hoffmann, Kupper, & Kunz, 2000).

One of the difficulties with re-establishing a 'well' identity is that one's self-appraisals and the appraisal of others may be disproportionately influenced by the initial crisis, symptoms and loss in functioning (Kroska & Harkness, 2006). Joseph and Linley (2005) have suggested that trauma-related information may be incompatible with existing models of self and world. This incompatibility provokes individuals into revising their pre-existing models of the world or self to accommodate for the trauma experiences or to assimilating the new information as consistent with pre-existing models. Importantly the process of assimilation may restore the previous model, while accommodation may lead to a re-development (either positive or negative) of one's assumptions.

Post-traumatic growth (PTG) can be defined as the "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (Tedeschi & Calhoun, 2004, p. 1), with growth occurring as a reaction to rather than a direct result of traumatic experiences. In contrast to the assumption of catastrophic impairment following psychotic experiences, research exploring narratives surrounding the development of schizophrenia found that the process of being unwell allowed individuals to develop personally and become more themselves (Barker, Lavender, & Morant, 2001).

While both assimilation and accommodation of trauma-related information may alleviate PTSD symptomatology, it is argued that the process of PTG can only occur through the integration of trauma-related information within one's existing models of the world, self and/or others (Creamer, Burgess, & Pattison, 1992; Joseph & Linley, 2005; Rachman, 1980). This distinction is suggested to relate to differences in emphasis within meaning-making. Namely, for PTG to occur one must make efforts to come to an understanding of the personal significance of the event rather than simply comprehending what occurred (Joseph & Linley, 2005). Linking these concepts to psychosis one can infer that an individual may be changed by a psychotic experience (either positively or negatively) though not fully comprehend it, or may have a clear comprehension of the event yet their assumptions about themselves, others or the world remain largely unchanged.

Psychosis and Families

Research that has addressed the impact of having a family member with psychotic symptomatology has predominantly investigated how the individual is a burden on the family. Research has consistently demonstrated higher levels of distress in 30-60% of relatives due to the increased demands of caring for a family member with a diagnosis (Birchwood & Cochrane, 1990; McGilloway, Donnelly, & Mays, 1997).

Care-giving and burden

“Caring is an inherently unequal relationship: the person doing the “caring” has more responsibility and has more to do than the person being cared for, who is to some extent dependent” (Kuipers & Bebbington, 2005, p. 217). The MH charity Mind cautions against the use of the term carer as it may hold an inherent bias:

“If you are sane, you have mothers, fathers, siblings, partners, children. But if you have mental health problems, then these people become ‘carers’... the relationship between people with mental health problems and their nearest and dearest cannot be reduced to 'carer' and 'cared for'. Reciprocity continues to exist where a member is disabled as a result of their mental health problems.”
(R. Perkins, 2011).

Not discounting the undoubted strains of being a carer (Kuipers, Onwumere, & Bebbington, 2010), the mis-use of the terminology has the potential to pathologise normal family relationships and expectancies. Indeed, a recent study which asked siblings of adults with a diagnosis of schizophrenia about their future expectations of care-giving indicated that siblings:

“expect to help their brother or sister during an illness, invite him or her to participate in family holidays and celebrations, listen to his or her problems and provide advice... Siblings were less likely to expect to help with more hands-on and ongoing caregiving tasks”.

The authors go on to define their results as ‘optimistic’, in that they “do not suggest that adults with schizophrenia will be abandoned by their siblings” (Smith, Greenberg, & Mailick Seltzer, 2007, p. 34). A potential danger of such assumptions is suggested by research demonstrating that evaluation of burden is associated with carers’ subjective psychological *appraisals* of their relative, rather than the severity of the individual’s illness symptoms (Raune, Kuipers, & Bebbington, 2004).

Given the emphasis within MH services to reduce symptomatology, it is surprising that care-giver burden paradoxically seems to be more associated with contact time

rather than symptoms. Research has found that the assessment of burden actually increased when symptoms decreased if there was a corresponding increase in contact time (Rosenheck et al., 2000). A large-scale Dutch study also found that reducing symptomatology and contact time reduced burden, but also indicated coping capacities play a central role in reducing perceived relatives' stress (Schene, van Wijngaarden, & Koeter, 1998).

The concept of expressed emotion (EE), used to describe relationships characterised by criticism, hostility and emotional over-involvement (Barrowclough, 2005), has been a focus for much research in this area. Individuals with high EE tend to rate subjective burden as higher, have a higher use of avoidant coping and perceived lower functional ability in their relative, as opposed to relatives with low EE (Raune et al., 2004). Additionally, relatives who demonstrate high levels of criticism are not only more likely to make blaming attributions concerning their relatives, but are also more likely to attempt to exert a higher degree of control over them. This is associated with increased distress, reduced self-esteem and increased likelihood of relapse (Barrowclough & Hooley, 2003).

However, there is growing evidence that EE should be considered bi-directional, that is dependent on both sides of family-service user (SU) interactions (Goldstein, Rosenfarb, Woo, & Nuechterlein, 1994; White, 1987). *“Thus a complementary or alternative hypothesis is that adults with schizophrenia with higher levels of life satisfaction interact in ways that elicit more positive responses from others”* (Greenberg, Knudsen, & Aschbrenner, 2006, p. 1772). The relationship between increased perception of difficulties and reduced well-being is not unique to

experiences of psychosis but has also been well documented in relation to physical illness (Weinman, Petrie, Moss-Morris, & Horne, 1996).

Awareness of attribution and appraisal styles opens up the possibility for carer supportive interventions which may promote a virtuous cycle (Kuipers & Bebbington, 2005). One way of pursuing such an outcome is to shift the field of focus in research from burden to addresses other areas, such as the positives of caring and to include the perspectives of SUs.

Aim of the Review

The review will now critically evaluate the research which has addressed how individuals with psychotic symptomatology can support and contribute to their families. As there is a relative paucity of literature relating to how young adults with psychotic symptoms or individuals with FEP contribute to their families, the review will include studies which have focused on how individuals with psychotic symptoms may positively contribute to their families, irrespective of age range.

Contribution

Bulger and colleagues (1993) conducted the first study to identify gratification as a potential result of caregiving, sampling 60 parents of adults with a diagnosis of schizoaffective disorder or schizophrenia (with an average of 15 years of MH difficulties). Data were also gathered on burden, conflict, intimacy and quality of interpersonal relationship from parents to assess the impact on gratification. The study used a mixed methods design, with regression analysis indicating that intimacy best predicted gratification, while conflict predicted burden. While parents indicated a “great degree of gratification from care-giving” (p. 263), the positive aspects of

caregiving was described as area that tended to be overlooked. While SUs were described as requiring 'minimal assistance' in daily activities by parents, no data was gathered regarding their contribution to the family however.

A large-scale American study sampling 725 service-users (median age 40) and relative dyads was the first to address whether individuals with MH difficulties (65% of whom had a diagnosis of schizophrenia/schizoaffective disorder) contributed to their families (Greenberg, Greenley, & Benedict, 1994). The authors highlighted the importance of collecting data from both SUs and relatives, as previous research on burden had solely focused on relatives' perspectives (though no direct comparisons regarding agreement between dyads was made). While sampling of relatives included partners, parents, siblings, and adult children, the degree of contact for some may have been minimal as the inclusion criterion for relatives was 3 or more face-to-face or telephone contacts a year. The study used a non-standardised adapted 4-point Likert-style questionnaire which examined perceived contribution across 8 areas. The results indicated that both individuals and relatives reported a substantial degree of contribution, particularly individuals and relatives who lived together, which the authors suggest related to increased opportunities for contribution amongst these individuals. The authors highlighted that family expectation should be an area for future research, as it is likely to influence contribution.

A second paper by Greenberg (1995) using a similar methodology to the first, sampled 105 mothers of individuals with 'serious mental illness' (73% with a diagnosis of schizophrenia). Data regarding family expectations were not collected, nor did the study include SUs perspectives. However, the majority of individuals were

provided at least 'some' ongoing support. Although the use of regression analyses may have been inappropriate in the context of the 3-point Likert scales (Russell & Bobko, 1992), the findings suggested that lower subjective burden predicted higher perceived support.

Horwitz (1994) paper was the first study to introduce the idea of reciprocal contribution, in an exploratory study involving 85 individuals with a diagnosis of schizophrenia (85%) and bi-polar disorder (15%) and 108 of their siblings. A further paper using data from the same sample included 66 individuals with psychosis (18-55 years old) and an unclear number of their relatives (parent and/or sibling). The research actively rejected the assumption of "active givers and passive receivers of support" (Horwitz, Reinhard, & Howell-White, 1996, p. 149). The study measured contribution across seven areas, demonstrating a high correlation (.5 to .6) between the degree of support-giving and support-receiving between SUs and relatives. Interestingly, the study found that "more symptomatic patients in the sample do not provide less nor receive more, support" (p. 159). Instead, the analysis indicated that the best predictor of support-giving behaviours irrespective of whether individuals were SUs, siblings or parents was support-receiving. Unusually, given the findings supported a reciprocal exchange the authors go on to make an argument that reciprocal support should be viewed as largely symbolic, and therefore may not necessarily involve equivalent transactions.

A further study sampled 93 parents (aged 50-70, 80% mothers) to assess perceived support, assistance and possible rewards of caring for adult children with a diagnosis of schizophrenia or schizoaffective disorder (Schwartz & Gidron, 2002). The

description of the design and analysis was unclear which would make replication difficult. Parents' mean scores on a measure of gratifications of caregiving were significantly higher than mean scores on measures of instrumental and emotional support received. While the authors interpret this finding as indicating that parents perceived their own caregiving activities as being more fulfilling, such inferences are not clearly supported by the data or study design. Though the results seem to suggest that increased symptomatology predicted decreased contribution (in contrast to Horwitz (1994, 1995)), the symptomatology measures appear to have measured stigma endorsement rather than symptoms. Unlike previous studies' hypothesis of reciprocal contribution, parents in this study perceived increased levels of contribution when they supported their children less. The authors suggest that caregiving rewards may be a function of the perceived responsibility for and meaning ascribed to caregiving, and advocate the use of interventions to alter such appraisals. These inferences were not supported by the findings however as no data was collected on these factors.

Tennakoon and colleagues (2003) was the first study to address possible rewards of caregiving in relation to FEP. However the brevity of the article precludes an assessment of the validity of the findings. For example while the study sampled 40 SUs and 40 relatives, no SU data is discussed. While there was mention that caregivers valued the contributions made by their relative to the household, shared interests, and their strength in coping with the illness, there is no indication of how representative these views were. Unfortunately, as there is no mention of the specific statistics used and a full description of the study has not been published elsewhere, it is not appropriate to draw any implications from the research.

A preliminary UK study which interviewed 10 siblings (80% female aged 16-30) of individuals with FEP, found that siblings identified positive gains from the experience of having a relative with FEP (Sin, Moone, & Harris, 2008). While the study is described as 'phenomenological' it seems to consist of a basic thematic analysis, with little experiential description. Contribution was not focussed on, as the interview schedule had been developed from previous research which focused on subjective and objective burden (Sin, Moone, & Wellman, 2005). Specific positives related to changes in the individual: increased personal development; understanding; sensitivity; and considerateness; as well as changes in the family unit; increased familial closeness and resilience. Interviews indicated that siblings had experienced high levels of stigma and embarrassment, which made sharing or getting support difficult. The study highlights a specific need for services to accommodate and support siblings. The routine use of genograms as first contact is suggested as a means of highlighting potential need in siblings.

A recent UK study was the first to use grounded theory methodology to explore whether individuals with psychosis positively contribute to their families (Coldwell, Meddings, & Camic, 2010). This well-described study suggested that individuals can and do contribute to their families. The proposed model suggests that contribution is something that is lost in the early stages of psychotic experiences but can be gradually regained. The process of re-growth is shaped by the individual, familial and societal factors as well as the availability of opportunities to contribute. The study interviewed 6 individuals (aged 30-50) with psychosis and 6 relatives (aged 40-70) although not all interviewees were related. The degree of contact for some participants may have

been minimal as participants were included as long as they had at least 3 face-to-face contacts with their relative per year. Additionally as the participants in the sample had prolonged histories of MH difficulties (10-20 years) (Meddings, personal communication), it may not represent the experiences of individuals with shorter histories or more recovery orientated services (NIMHE, 2004).

Limitations and directions for future research

While the research supports the position that individuals with psychotic symptomatology can and do contribute to their families, the strength of this finding is limited for a number of reasons. A number of the studies are limited by the use of non-standardised measures, questionable analyses and conclusions beyond the supported data. The majority of studies have neglected to include a SU perspective.

The exclusive use of cross-sectional designs in the existing research may explain why Greenberg et al's (1994) suggestion that research examine the role of familial and individual expectation regarding contribution has yet to be fully addressed. Additionally, while a number of the studies attempted to infer causal connections between factors, longitudinal designs would have been better placed to test out these relationships.

Almost all the studies to date have focused on SU who were middle-aged and had long histories of psychotic experiences. None have addressed what factors help or hinder acts of contribution during FEP. Given Coldwell et al's (2010) sample, it is unclear whether the proposed model accurately describes acts of contribution in individuals with briefer experiences of psychosis and their families, suggesting a clear area for further research. While the research has to some extent followed Kuipers and

Bebbington's (2005) suggestion to include a wider range of perspectives (e.g. carer, individual with symptoms and other family members), given that individuals may be more influenced by peer-group rather than familial perspectives in emerging adulthood, this is likely to be a worthy area of research. Another area which appears to be absent is MH professionals' perspectives relating to contribution (Coldwell et al., 2010).

It is also unclear if the suggested differences between studies in the relationships between factors in contribution are due to altered methodologies, differences in the psychometric properties between measures or cultural differences. Given that research has demonstrated cultural difference in the path to recovery (Hopper, 2007), establishing cultural norms in regards to contribution is a suggested area for research.

Lastly there is an implicit assumption in the research that the majority of individuals who've experienced psychotic symptoms require caregiving (Perkins & Repper, 1998; Sayce, 2000). A large-scale population based study would be best placed to assess the accuracy of such assumptions.

Implications for clinical psychology

A recent (May, 2011) literature search using the search keywords "burden" and "psychosis" elicited 411 results on the Web of knowledge database, only 5 of which mentioned positive aspects of psychotic experience. It is noteworthy that the majority of the articles that addressed either positive contribution or PTG following psychotic experiences went to considerable lengths to justify the focus of research. The predominant focus on burden and passivity systematically underemphasises clients' strengths and the integration of positive characteristics, which increases low self-

image and self-stigma. Focusing on active givers and passive receivers hinders the development of an evidence base demonstrating the support that people with a diagnosis can offer to their families and friends (Kuipers & Bebbington, 2005). This emphasis in research in effect may increase the societal expectancy that MH difficulties are synonymous with catastrophic permanent impaired functioning for the individual and an unwelcome burden for society and their families.

Given the suggested relationship between noticing positive contribution and familial and individuals' wellbeing (Coldwell et al., 2010; Greenberg et al., 1994), there is a clear need not only to increase the field of research in this area, but for such research to gain wider both professional and societal recognition. One of the factors that may hinder the development of contribution is the assumption that it does not occur. It is also hampered by dichotomous assumptions surrounding the roles of (active) caregivers and (passive) receivers of care. Clinical psychologists may counter such assumptions simply by asking about positive contribution in therapeutic work, or highlighting this possibility to other MH professionals. Additionally once there is a clearer understanding of the factors that promote and hinder contribution in individual and families this opens up the possibility for tailored intervention.

Conclusions

The continued dominance of a burden perspective suggests there is a clear need to establish a firmer theoretical foundation for the occurrence of acts of positive contribution in individuals and families who have been impacted by psychosis. There is a clear need to establish how individuals and family members who have been impacted by FEP view positive contribution, what factors promote or hinder these

processes and whether acts of positive contribution are lost or subsumed in the early stages of psychotic experiences.

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Section B: Empirical paper

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How individuals with first-episode psychosis positively contribute
to their families. A grounded theory analysis

Section B: Empirical Paper
Word Count: 7999 (plus 6 additional words)

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Abstract

Aim. The aim of this grounded theory study was to explore whether individuals who have experienced first-episode psychosis positively contribute to their families. Additionally, the study aimed to construct an explanatory model of how positive contribution to families is viewed and supported following first-episode psychosis.

Method. Fifteen participants took part in the study. Seven had direct experience of psychosis, seven were relatives and one was a partner of an individual with direct experience. Participants were interviewed separately, with the accounts analysed using Charmaz's version of grounded theory (Charmaz, 2006).

Results. The constructed theory suggested that individuals who have experienced first episode psychosis can and do contribute to their families, and that such contribution when noticed and valued can lead to an increase in well-being. The model suggests that contribution is shaped by the self-concept, the impact of psychosis, the opportunity for contribution and whether it is noticed.

Conclusion. The constructed theory extends current research, and suggests that contribution can positively impact both the individual and family. Limitations and clinical implications of the research are explored and suggestions for further research given.

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Introduction

First-episode psychosis (FEP) refers to the first time a person experiences psychotic symptoms, with 80% of individuals experiencing their first-episode in adolescence and early adulthood (World Health Organisation, 2004). This tends to coincide with a stage of development suggested to demarcate adolescence from full adulthood, known as ‘emerging adulthood’ (Arnett, 2004). For most young adults this represents a time of instability and identity formation, in which possible future life-styles and roles may be explored. One of the primary tasks facing emerging adults is the development of goals and aspirations (Arnett, 2004). However the challenges and opportunities encountered at such critical transitions may shape the kinds of goals that they construct (Little et al., 2007).

One of the reasons why psychotic experiences may be so difficult to adapt to is that they constitute a non-normative or unexpected life event. There may not be any readily available roadmaps or societal reference points on which individuals or their families may draw to re-orientate goals and expectancies. Instead individuals and families may be forced to actively compensate and develop these personally (Wrosch & Freund, 2001). How individuals, families and society make sense of, view and respond to experiences of psychosis may therefore have serious consequences for the person’s identity formation and future wellbeing.

Charmaz (2002), writing from a social constructionist perspective, has explored the effect of chronic physical illness on individuals’ identity, or sense of self. “Self” here may be conceptualised both as a process and as an object (Gecas, 1982). That is selves are constructed through the processes that an individual engages in (for

example, thoughts, feelings, behaviours), with the self-concept (self-as-object) emerging out of the stability or consistency of these processes (Charmaz, 1999). Over time they become enduring meaningful references both to the individual's sense of self (Charmaz, 2002) and how they are viewed by others (Hewitt, 1984). For most individuals with chronic illness, the self-concept did not immediately change upon receiving a diagnosis, but gradually altered as the illness or treatment regime forced individuals to recognise that previously taken for granted self-as-process actions had changed or were no longer possible.

While such theories have yet to be applied to the experience of psychosis, it is possible to imagine that by failing to separate “problematic attributes, ideas, assumptions, beliefs, habits, attitudes, and lifestyles from the patient's dominant identity” (Tomm, 1989, p. 55), individuals, families and society may incorrectly assume that an individual experiencing psychosis can no longer continue or maintain the roles which previously gave them a sense of wellbeing and success (Slade, 2009). “Your label is a reality that gradually shapes an identity that is hard to shed” (Leete, 1989, p. 199). Through such shaping individuals may lose the freedom to pursue dreams and life goals as their identity becomes synonymous with that of mental patient (Cooke, 2008).

By framing psychosis as a long-term and chronic illness, and focussing on acute crisis and rehabilitation, treatment interventions have historically overlooked the possibility that the early phase of psychosis may constitute a critical period when the trajectory of difficulty and outcome may be fundamentally altered (Birchwood et al., 2000). Birchwood and colleagues suggest that this critical period hypothesis presents

important opportunities for limiting difficulty and distress. They recommend changing the emphasis away from crisis intervention and withdrawal to ongoing intervention for a suggested minimum of 3 years. This duration is considered necessary as a means of sustaining and nourishing continued positive change, and fits with more recent service-user led conceptualisations of recovery. These regard recovery as more than symptom remission; rather it refers to “the process of regaining active control over one’s life” and may involve (re-)discovering a positive sense of self, coping with and seeking support for distress or disability, finding meaning in experiences, resolving intra- or interpersonal issues, and taking on meaningful social roles (Care Services Improvement Partnership, (2007).

Families can play an important role in promoting recovery and are considered an essential part of any interventions offered (National Institute for Health and Clinical Excellence, 2003, 2010). However, much of the research examining the impact of having a family member with psychosis has investigated the extent to which an individual is a burden on the family. Having a family member with a ‘serious mental illness’ has been described as a “pivotal, catastrophic and cumulative” stress for the family (Lukens et al., 2004, p. 489). Not discounting the undoubted strains of being a carer (Kuipers et al., 2010), focusing on active care-givers and passive care-receivers may serve to promote low self-image and self-stigma amongst individuals with psychosis (Ahmed & Boisvert, 2006) and may hinder the development of an evidence base demonstrating what people with a diagnosis can offer to their families and friends (Kuipers & Bebbington, 2005).

A small but growing body of research has demonstrated possible positive aspects of living with mental health difficulties. Individuals with a diagnosis of schizophrenia for example have been shown to make a positive contribution to their families, through practical/emotional support or by promoting personal growth in their relatives (Coldwell et al., 2010; Greenberg et al., 1994; Horwitz et al., 1996; C. Schwartz & Gidron, 2002). While the research supports the position that individuals with psychotic symptomatology can and do contribute to their families, the strength of this finding is limited for a number of reasons. A number of the studies are limited by the use of non-standardised measures, questionable analyses and conclusions beyond the supported data. The majority of studies have neglected to include a SU perspective.

A recent UK study used grounded theory to explore whether individuals with experiences of psychosis (of an average of 10-20 years duration) positively contribute to their families (Coldwell et al., 2010). This well-described study which involved interviews with 6 individuals with experience of psychosis (aged 30-50) and 6 relatives (aged 40-70) suggested that individuals can and do contribute to their families. The proposed model suggests that contribution is something that is lost in the early stages of psychotic experiences but can be gradually regained. The process of re-growth is thereby shaped by the individual, familial and societal factors as well as the availability of opportunities to contribute. While such research is promising, it is unclear whether the theory proposed represents the experiences of individuals with shorter histories or in more recovery orientated services (NIMHE, 2004).

Increasing an information base relating to possible positive contributions may help counter negative stereotypes while at the same time enhancing professional and public

perceptions of people with mental health difficulties, as well as increasing self-esteem in these individuals (Greenberg et al., 1994). Increasing our understanding of how positive contribution is negotiated in first-episode psychosis is particularly relevant, as greater flexibility in the capacity to try on and reject specific identity roles in emerging adulthood, may enable interventions that avoid the development of future 'spoilt identities' (Goffman, 1990).

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

- explore whether positive contributions are lost or subsumed in the early stages of first-episode psychosis
- identify what factors maintain, encourage or increase the recognition of positive contribution following first-episode psychosis
- develop an exploratory model explaining the relationships between these factors and views.

Methodology

Participants

Fifteen participants were interviewed. Participants either had experienced first-episode psychosis (FEP) or were a family member or partner of someone with experiences of FEP (Table 1). For the purposes of clarity the term 'individual' will hereafter be used to describe individuals who have experienced FEP, and the term 'relative' will be used to describe family and partners. The final sample comprised of four dyads, two triads and one singleton. All individuals had ongoing contact with and were recruited through Early Intervention in Psychosis (EIP) services. Individuals were considered by services to be stabilised and not in immediate crisis or distress,

although the majority had ongoing positive symptomatology (one participant had not experienced symptoms for six months). All individuals had been in contact with EIP services between 6-24 months before interview, had at least one hospital admission and/or been sectioned. For the purposes of anonymity, quotations will indicate only whether the participant was an individual or relative and where individuals are referred to within the text the female gender will be used. For further methodological considerations see Appendix-II.

Procedure

Potential participants who were deemed stable by the EIP service staff were approached by a member of the EIP staff team, who briefly described the study and provided the information and frequently asked question sheets (see Appendix III). Interested participants gave consent for the EIP staff member to pass on their contact details to the main researcher. The main researcher waited at least 48 hours before approaching the potential participant to discuss the project and seek informed written consent. This was obtained from each participant before the interview took place.

Data was collected through semi-structured interview. Interviews were audio-taped and lasted between 40 and 90 minutes. The interview schedule was developed through service user consultation and drawing on relevant research in the area. The key questions from the interview schedules were always asked but following standard semi-structured interview practice the chief investigator explored certain responses in greater detail, to explore emerging themes. Following standard grounded theory (GT) practice after the first 4 participants were interviewed (2 individuals and 2 relatives), the interviews were analysed to ascertain if any of the questions needed to be altered

(Willig, 2008). This process was repeated after every 2-3 subsequent interviews, as a means of directing theoretical sampling and assessing data saturation.

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

Analysis

GT was used to analyse the data due to the exploratory nature of the research (Denscombe, 2007) and as it is a appropriate measure for exploring interpersonal development and change (Charmaz, 2006). GT allows for variability in the range of sources (individuals and relatives), which is believed to enable a richer theoretical model. Reflexive research diaries, memos and auditing were used to ensure the

quality and reliability of the analysis. Through the use of 'bracketing', the researcher periodically reviewed whether or not biases were becoming apparent in the emerging model.

The study endorsed a constructionist view of GT (Charmaz, 2006) but also drew on the writings of Strauss and Corbin (1998). It therefore recognises that the resulting theory is an interpretative act, dependent on the researchers view (Charmaz, 2006). Early transcripts were coded using line-by-line open coding. Codes and data were then examined using the constant comparison method, with codes then grouped into categories. Themes were thereby constructed from the data and explored in subsequent interviews. This allowed a more in-depth understanding of emerging categories. The plausibility of the theoretical model was then reviewed against all transcripts, using selective coding to re-check relevant data and fit. While the author was aware of the use of axial coding (Strauss & Corbin, 1998), it was not used as it was felt to constrain the constructed model (Charmaz, 2006). Memos and journals were used to highlight properties and dimensions (sub-categories) of emergent categories and record the thinking underlying the category development.

The collected data were coded and categorised so that the theoretical model which best explains the findings could be constructed. Credibility of the findings were evaluated using Yardley's (2000) guidelines.

Ethical and R&D approval

Ethical approval for the project was obtained from NHS research ethics board, Research and Development approval for the project was obtained from two NHS trusts.

Results

Meta-categories: contribution, self-concept, impact of psychosis, opportunity and noticing

The data suggested that the process of contributing in FEP could be conceptualised and understood with reference to five meta-categories or processes. These were: the natural occurrence of acts of contribution even during crisis (Contribution); how individuals related to themselves (Self-concept); the significance and search for meaning related to the experiences (Impact of psychosis); how acts of contribution were supported or promoted (Opportunity); and the recognition or value placed upon such acts (Noticing). The 5 meta-categories encompassed more subtle processes illustrated in the categories and sub-categories below (see Table 2)

Table 2: Main categories of constructed theory.

Meta-categories	Categories	Subcategories
Contribution	Practical support Emotional support Family enhancement Personal enhancement Reciprocal exchange	
Self-concept	Self-as-process Psychosis-as-self Growth-in self A normal-self	
Impact of psychosis	Problem conceptualisation Recovery Stigma	
Opportunity	Managing difficulties Perceived ability to cope Expectation	
Noticing	Perceptual bias Relationships and context Valuing	Negative bias Focusing elsewhere Emotional betrayal Communication Closeness

Constructed theory

The data suggested that while individuals do positively contribute to their families, such acts frequently go unnoticed. Acts of contribution varied amongst individuals and were influenced by: the self-concept; opportunity; and the value placed on such acts. The impact of psychosis strongly influenced an individual's self-concept in addition to affecting an individual's perceived ability to cope and their own and others' expectations around contribution, both of which were facets of opportunity. The model indicates the absence of a direct relationship between the degree of support for an act and the recognition and appraisal of its value. Rather it suggests that whether acts are recognised and valued is mediated by certain perceptual biases, one's relationships and the context in which individuals find themselves (see Figure 1).

Contribution

Data relating to nature of contribution fell into five sub-categories which will be described below. Overall, the interviews indicated that the majority of individuals contributed at an equivalent level to their peers and family members. Only one individual was considered to be contributing at a level less than peers, while three of the relatives indicated that their loved one was contributing more than siblings or peers:

I think already she does far more than what most teenagers would. (Relative)

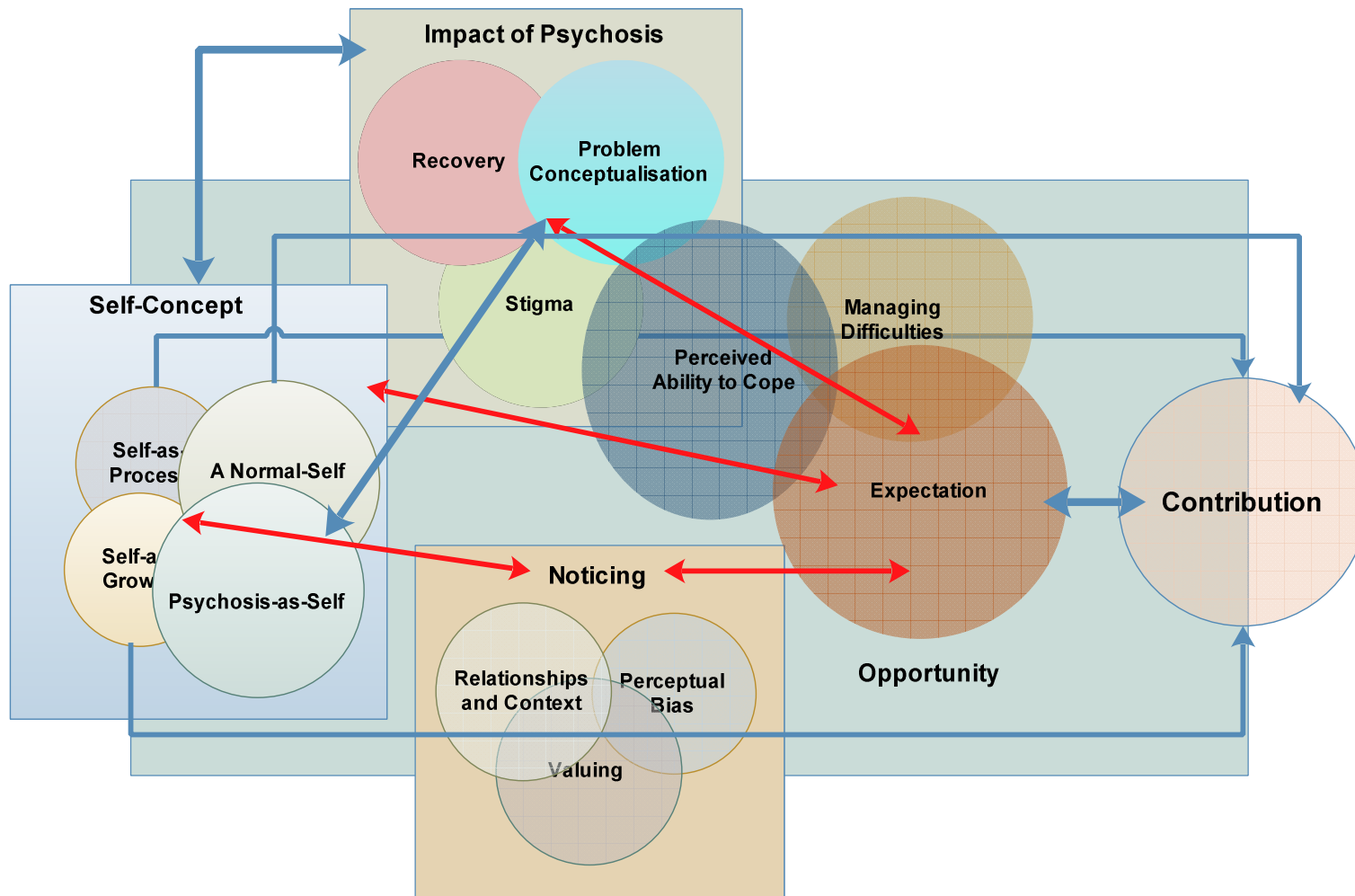


Figure 1: Diagram of constructed model. Red arrows represent pathways which depend on changes in context and relationships to occur.

The interviews suggested that while there is a reduction in acts of contribution during crises, these acts may not cease altogether.

I mean when she was very ill she was doing art at the college, which is something she did, A-level, you know, so she was, she did some very nice sort of pieces... we've got the sign on the front of the house, pottery sign. So she certainly was doing stuff like that and still able to do creative work. (Relative)

Practical Support

Individuals were described as contributing in numerous practical ways including: care-giving; financial support; housework and cooking; sharing their educational, technical or creative skills base with others.

I do the housework with my mum, every day. Either when I come home from my volunteer job or on my days off. And then I sometimes cook dinner. But yeah, I help around the house a lot and do a lot of sewing and craft things. (Individual)

Emotional support

Individuals and relatives both gave frequent and rich descriptions of the emotional support and companionship that individuals contributed. The descriptions centred around emotional closeness, being someone to share things with, dependability and having a good sense of humour.

So [she] knows everything about that, and 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. And just the efforts that she makes, make you know you're loved. She goes to a lot of effort to let you know that you, yourself, are valued and loved. (Relative)

Family enhancement

The interviews indicated that families had benefited from the experiences in a number of ways, such as: becoming closer as a family; finding inner strength and resilience; highlighting the need for changed family dynamics. There was a largely consistent description in relation to specific acts of contribution between individuals and relatives.

“Well I think her personality and the way that she has been so resilient and got through all these difficulties... is... very optimistic, makes you feel that as a family we can cope with difficulties when they do arise, even if there are severe difficulties. You know, 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)

Personal Enhancement

The interviews indicated that relatives may experience personal enhancement due to the experiences and relationship with their loved one. Such enhancement related to: increased empathy and understanding; increased self-worth through supporting loved one; increased knowledge and skills base; and experiencing a greater appreciation and value in life. Seeing a family member overcoming crises and managing new challenges also acts as an incentive for family members without difficulties to do more.

It certainly enlightened me into things that I'd never experienced before. Perhaps a little bit more conscious of people's emotions and things perhaps.
(Relative)

Reciprocal exchange

The interviews also suggested that the nature of contribution tends to involve a reciprocal exchange of support or contribution. For example, three of the individuals were long-term care-givers themselves.

I've always got a feeling that they can rely on me and if I let them down, they're not going to want to rely on me more, so... I try to be a good friend

(Individual)

Self-concept

The data suggests that individuals' relationship to self could be conceptualised in terms of 4 lenses: self-as-process; psychosis-as-self; growth-in-self, and a normal-self.

Self-as-process

The interviews indicated that there was a strong relationship between self-as-process and the nature of contributions which individuals engaged in. Self-as-process related to descriptions of an individual's habitual actions, feelings or thoughts, which acted as a reference to the individuals' lasting character. These processes tended to be viewed as an almost automatic response to given situations.

But she always had this desire, like even when she was extremely ill she was making appointments at university and getting places, even though she'd given up one university place, which we'd actually encouraged her to do because we felt it was too much for her. (Relative)

Psychosis-as-self

Being perceived or labelled as psychotic seemed to constitute an immediate catastrophic redefinition of identity for most participants. Most participants seemed to

suggest that the previous sense of self had been replaced with one that was defective, shameful, unknowable, possibly violent and constitutionally “not normal”.

The name doesn't help. It's psycho, cause that's the only thing people hear is that... and when I got told I just thought I'm a psycho. Psycho, psycho, psycho, and you just think of someone that goes killing people and...does crazy things... Well I thought they'd got it completely wrong... I thought I'm sicker than I thought I was. (Individual)

The interviews indicated that following this redefinition, almost all aspects of self-hood were filtered or defined in relation to the psychosis-as-self. The strength of this attribution seemed to be influenced by the degree to which individuals/relatives endorsed the stigmatised view and the perceived discrimination individuals would experience if others knew that he or she had psychosis. A common response to this redefinition was to attempt to hide it from others.

Growth-in-self

In contrast to the psychosis-as-self attribution, all but one of the interviews indicated that the individual had grown and developed. Such growth related to increased maturity, empathy, responsibility, strength, resilience, a better sense of humour and a better appreciation of life. Individuals attributed this growth to either the normal course of maturation or to changed interactions with others or as a direct result of their experiences.

Well I just think if I can get through that and having them horrible experiences every day all day then I can do anything really. (Individual)

For some making a connection between psychosis and teenage years seemed to make the experiences more tolerable, possibly because there was explicit belief that the

individual might simply grow out of psychosis. For older individuals, as well as individuals whose psychoses were feared to be permanent, relatives seemed to have greater difficulty noticing growth.

Well I think that, you know, with teenagers you just know you're going to experience all these different things and you never know when they're teenagers. But now she's out of the teenage years [laughs], you know, she's [age] so... yeah I'd say it'd be more of a problem. (Relative)

A normal-self?

The interviews indicated that following psychotic experiences there was enormous pressure to appear normal. The normal-self tended to be described as a kind of artifice or illusion which prevented others knowing or reacting to the psychosis-as-self. This pressure to present a 'normal' front seemed to be derived from feared or actual experiences of discrimination. For some in order to appear 'normal' they would deliberately monitor and control their emotional display to others, because of fears over how such displays would be interpreted. For others being 'normal' was successfully hiding their psychotic experiences, such that they would then be treated by others as normal.

Yeah. I'd rather be treated as if I was normal because if they treat me like I'm normal, I'll act like I'm normal [laughs]. If they treat me like a sympathy case I'll go round feeling sorry for myself. (Individual)

The awareness that they were "acting" seemed to reinforce rather than assuage individuals' sense of difference. For some individuals the way out of this bind was to accept the non-normal aspect of self, at which point they could start to ascribe value to their actions. One individual used the metaphor of 'coming out' to explain the difference between being normal and acting normal.

Yeah 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. And if anything, just language-wise and philosophy-wise, is who you're being... do the actions make the person? Because if that's the case then you are a heterosexual female. But what does that mean? Because you're not a heteros... so you get into this whole world of you don't know who you are or who you want to be, and then obviously the way you react to other people is the same. If you don't know who you are, they're not going to know who you are. (Individual)

Impact of psychosis

The impact of psychosis on the individual and the family was predominantly described as being both a source of growth and a problem. While one individual indicated that the growth out-weighed the problem and they would choose to continue to have the experiences, this view wasn't endorsed by others. The interviews suggested that whether or not growth was recognised was linked to participants' search for meaning in relation to the experiences. Those who did not actively seek to make sense of the experiences tended to underemphasize or discount growth and positive aspects, and to de-emphasise the individual's agency in relation to the problem and recovery.

In contrast participants who reported engaging in a search for meaning were also more open to noticing growth and positives during the interview itself, even if they had not noticed them previously. Overall, they tended to have less binary perceptions of events, tending to see them in a wider context.

I suppose in a way, it was not good or bad, because although it was bad at the time and hard to deal with, I did learn something from it and I suppose that is probably maybe a useful lesson to have learnt how to control your anger. And not to belittle people by it. (Individual)

In making sense of their experiences, individuals grappled with the issues of problem conceptualisation, stigma, and recovery.

Problem conceptualisation

Problem conceptualisation involved looking to find a cause or reason for the experiences. The data indicated that most individuals initially knew very little about psychosis and therefore tended to base initial understanding on either medical or social descriptions.

Well I don't understand it fully. I mean all I understand is that, you know it is a chemical issue and they're given a different medication for it and it seems to be sorting it out and... Yeah, hopefully that'll be the end of it. (Relative)

While the majority of participants indicated that they did not feel that an individual's diagnosis offered a complete explanation, it was often used as a starting point for how to conceptualise the problem.

Well post-traumatic stress disorder wasn't diagnosed until... about five months after the psychosis was diagnosed. So that helped me to understand a bit more... and I felt a bit relieved because there was a reason, you know, there was a reason for the psychosis. Whereas when they said 'oh she's got psychosis depression,' you're left thinking well why? What causes it? Why did it happen? (Relative)

The interviews suggested that developing an understanding of the experiences enabled participants to come to terms with and draw positives from those experiences.

once it's become less raw and probably less frightening and you know more about it, I think in my eyes, when I knew more about it, it just helped me move on. Accept it. Accepting was probably one of the hardest things. Accepting what happened. Accepting what it was all about. (Individual)

Recovery

Participants held a variety of views in relation to recovery. Conceptualisations generally involved multiple aspects, including: changes in personal agency; increased communication; learning limits; greater closeness and intimacy in relationships; the absence of symptoms; medication; and renewing hope for the future.

Well again I suppose it's gradual... as I say at the stage when she's really ill you sort of give up hope in a way, you think that it's never going to get better. And so bit-by-bit you start to see her taking on things. (Relative)

The specific view of recovery tended to shape the relevance placed on particular acts of contribution. Participants who located recovery in medication placed less importance or value on increased contribution than on getting the medication right. Those who emphasised agency in relation to recovery tended to place a greater importance on acts.

I didn't realise how much it was affecting me, cause when I was doing the [previous job], I kind of thought this isn't what I want to do but just enjoy it for the moment because it's easy. And so you just look at the good things while you're doing it but then when I did get this job and now that I'm doing

well at it, I kind of feel like a weight's been lifted... and you don't realise.

(Individual)

Stigma

The interviews indicated that stigma and negative stereotyping can have serious negative consequences, not only for the individual but their relatives and their interactions with the world. The interviews suggest that the relationship to stigma and the associated feelings of shame can overshadow contribution and minimise the positive effect it may have on well-being and identity. That is even when individuals can notice contribution and the positive effect on well-being, if they adopt a societal view they view themselves negatively.

it does prove that just because some people are ill, it doesn't mean that they're useless and need to be locked away kind of thing and that is... that's what... that's just... just knowing that makes me feel good just thinking that. You know, there are other people and we are still... they're the things I just... I really don't like it and people... but then I would be like it, "I think you're weird". (Individual)

The interviews also suggested that individuals do frequently experience discrimination, and that such experiences can negatively impact contribution due to the associated embarrassment, withdrawal and avoidance.

I did get the odd comment made, but I don't know if it was in jest or not, I don't know if it was just me interpreting it wrong. Or... I did have one point where my Manager, they were asking everyone's opinion and he'd said in front of me 'Don't ask [name] because she's crazy,' and then no one asked me my opinion. (Individual)

Opportunity

The interviews suggested that the opportunity for contribution was influenced by how individuals and relatives experienced the impact of psychosis. Depending on their experience of the impact, the opportunity for contribution was shaped by their managing difficulties, perceived ability to cope, expectation and family context.

Managing difficulties

Symptoms and medication side-effects were described as both helping and hindering contribution. When symptoms became '*very intense*' it made contribution difficult. Individuals frequently spoke of the need to withdraw temporarily at these times but that such withdrawal also intensified feelings of isolation and loneliness. Increased control of difficulties was often associated with feelings of empowerment, self-efficacy and increased hope if these changes were ascribed to personal or family agency, rather than external agents (e.g. services/medication).

I've been able to contribute because the voices weren't controlling me enough to hide away, so I was able to go look after my Nan. (Individual)

For some, due to the nature of the symptoms, even with increased management it was hard to recognise or value one's abilities.

cause I was constantly being told how worthless I was [by the voices]. So that's why. And then as soon as I told someone about them, and then got them under control and everything with the tablets and people helping, it seems to be much better. But for being told two years that you're worthless, you didn't mean anything, nobody loved you and that... it's quite hard.(Individual)

Symptoms however did not always have negative consequences in relation to contribution but prompted some individuals to do more, which could lead to increased wellbeing.

when they were good voices I would... it would drag me out of being depressed. But now I understand that the voices are part of me, it helps me even more because it means like, when I do start feeling sad, when I'd like think about something, it is my own thoughts now. (Individual)

While most participants felt that medication had helped in controlling symptoms, they also mentioned side-effects, which could hinder contribution due to increased lethargy, difficulties staying awake and motor tremors.

She just didn't have the ability to paint, and one of the other problems she got with her new medication was hand tremors. So obviously with painting that's really not a good thing. (Relative)

Perceived ability to cope

The interviews suggested that facilitation of contribution seemed to be based on an evaluation of the potential gains and risks associated with the acts. Getting the balance right between overburdening and over-protectiveness seemed to be influenced by the strength of the reaction to the individual's difficulties. The interviews suggested that where the individual had attempted suicide or there was a strong fear of losing the person to madness, individuals and relatives tended to prioritise protectiveness or view increased freedom with more apprehension than those who did not hold these fears.

The pressure to make the right choice between enabling and disabling was captured in a number of interviews, two using the analogy 'giving some rope'. This highlighted

the feared consequences of increased agency, combined with a realisation that without such action growth and development would not be possible.

I gave her a bit of rope, because I had to. If she'd hung herself, I know it's the wrong thing to say, but that was the way I looked at it. I had to, because I couldn't have wrapped her up in cotton wool for the rest of her life. (Relative)

While participants indicated that they initially conceptualised this as an 'all or nothing' decision, the process tended to be described as gradual.

And initially that was really difficult, she wasn't, so I was doing it all for her. Then it got to the point where we were dealing with things together, now it's got to the point where she's doing [independent activities] These are things I never could have hoped for... ever. (Relative)

Expectation

While the data suggested that the expectation of contribution is heavily influenced by the acts of contribution that are currently occurring, it is also shaped by a complex relationship between the: problem conceptualisation; view of recovery; perceived ability to cope; self-concept; and noticing.

yeah, it's going to be a very long process, and I know she's definitely not ready to kind of do anything, even reducing the [medication]. And we're just kind of hoping to, obviously after college would be better as well because some of the pressures from that will be gone. (Relative)

The interviews indicated that though gradually increasing levels of contribution might raise expectations, it does not automatically being about alterations in appraisals. An individual might thus be expected to contribute far more than they did previously, yet perceptions of the individual and the situation might remain largely unaltered.

Shifts in expectation when they did occur however could bring about changes in other categories. Such shifts could happen when the act of contribution was dramatically beyond what was currently expected or when changes in others' expectations were brought to individuals' attention. The interviews suggested that this generally occurred through unplanned situations or through relationships outside of the immediate family.

and I think if maybe somebody else might have rung me, like my sister-in-law, I most probably would have told her. But because (Individual) had rung me first, I told her. (Relative)

I guess what did you take from that? (Interviewer)

That she can handle it. (Relative)

Noticing

The data suggested that while individuals continue to contribute following psychotic experiences and they are generally aware of their acts of contribution, such acts tend not to be the focus of attention, and can thereby go un-noticed or undervalued. This lack of noticing contribution is suggested to relate to three separate but often related perceptual biases: negative bias; focusing elsewhere; and emotional betrayal. The data also suggested that relationships and changes in context can counteract these attentional biases.

Perceptual Bias

Negative bias

The data suggests the presence of a negative bias which resulted in heightened sensitivity to noticing how the individual was being supported but decreased

sensitivity to noticing how they were supporting others. At its most extreme some individuals did not consider that they contributed at all.

I don't do anything, my mum just does everything for me, I just take.

(Individual)

Negative stereotypes could influence assumptions regarding the occurrence of contribution that seemed to prevent it from being noticed.

Yeah and it's funny, because when I read your form, I read it and I was really worried because it said what positive effects does [individual] have? And I thought oh my God, she's got psychosis, cause when I spoke to you I said 'what... I don't know that there is anything positive,' and then I thought about it and actually there is a lot that I didn't really appreciate that is positive.

(Relative)

Stigma awareness and actively working to resist the stereotype might cause one to fail to notice that the acts one is attempting to promote are occurring.

You see, the thing is, I think I've been so caught up in trying to make [individual] feel positive by saying to her 'well you've done this and you've done that,' that I've not actually thought about it myself. And you know, the positive effect that she has on the family... and she does. (Relative)

Focusing elsewhere

Participants indicated that occasionally they did not notice contribution and growth because their attention was directed towards other matters. This could include the exigencies of daily life, watching out for signs of crisis, or renewing focus on things that had been neglected on account of a crisis. While some participants felt reluctant to acknowledge growth as it was implicitly intertwined with thoughts of relapse, others found the opportunity for reflection helpful.

it [interview] helps you get a better understanding of it. It just solidifies it and also makes you feel better cause like going through all this stuff now makes me realise how much I do still contribute and how much I've got better, back to what I was before. ... cause normally in everyday life you don't question it as much and you don't sit back and reflect on it, you just get on with it.

(Individual)

Emotional Betrayal

Speaking specifically about contribution and growth which had arisen out of psychotic difficulties, one participant captured a sentiment that seemed to be an implicit element of the majority of interviews. That is, acknowledging such acts could feel like a betrayal of oneself. This seemed to be based on a fear that to acknowledge any positive aspects was tantamount to welcoming psychosis back into one's life.

cause whenever I think of it I just think how it's ruined my life, I don't think that it's done any good. So it's really hard to think of the good stuff, I'm sure there is. And actually, actually 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

Participants frequently described how changes in context or relationships led to increased opportunity and/or noticing of contribution. Relationships particularly with someone outside of the immediate family often enabled both individuals and relatives to attend to an individual's capabilities. A change in context could lead to increased noticing of contribution due to viewing the actions in a different light, while acts of

contribution could increase because such contexts allowed individuals to take up new roles.

when I sort of watched her with the adults at this centre, she was... very mature with them, very well organised, very caring and she seems to be able to sort of change herself... I don't know the words to explain it. The way she acts to be, you know within a different environment. (Relative)

Communication

The interviews suggested that communication plays a crucial role in supporting the development of contribution. Good communication seemed to allow individuals and relatives to alter expectations, increase the opportunity for and support the development of contribution.

Just basically yet again, communicating with her. If I knew it was getting too much for her then I'd step in and do more. And let her have a break. But it's, yeah, a lot of it was communication. (Relative)

Closeness

A lack of closeness and withdrawal and can mean that family members may fail to notice change and development when it does occur, or may unwittingly interpret actions based previous expectations.

Well, I think it's difficult for my husband because he's not been involved. And... I think he's got blinkers on so I don't think he'd ever see anything positive in it at all. (Relative)

Valuing

All but one participant indicated that acts of contribution tended to be taken for granted. As such acts were expected of the individual, the effort or value related to them was not always noticed. Noticing an individual's agency in relation to an action seemed to be a necessary precursor to ascribing the value to the act, and was also associated with an increased sense of wellbeing.

Contribution could be underappreciated if the acts became viewed as stepping stones towards larger goals such as recovery or employment. Thus if participants were focused on an end goal (e.g. being symptom-free), contribution might be appreciated only in relation to this goal. One participant linked continued employment with increased stress, at a later point relating stress to increased symptoms. The individual thus viewed continued employment, despite the associated increase in social activity and money, negatively as it challenged her goal of becoming symptom-free. Other individuals considered contributions not being valued as contributing to the original crisis. Conversely, being able to ascribe value to one's contributions could lead to significant changes in how individuals perceived themselves.

just, talking about it like, with you and that, it just shows me actually that's happened, but look how far we've come now. Cause I can say good things about myself and before I couldn't. 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 occurrence and development of positive contribution to families in FEP. The findings suggest that individuals with FEP can

and regularly do contribute to their families and friends. The interviews also suggested that the level of contribution should not be viewed as tokenistic, as most individuals were considered to be contributing equivalently or more than peers, which supports Coldwell et al's (2010) findings.

In contrast to Coldwell's study, the current findings would suggest that contribution not only continues to occur in the early stages post-crisis but may actually continue even during psychotic crisis. The participants also indicated that contribution irrespective of the degree of support gained, does not tend to be the focus of attention, and therefore seems to go largely un-noticed. Such focus may constitute a self-fulfilling prophecy as failing to notice/re-enforce contribution may lead individuals in time to reduce or stop contributing. The model would suggest that failing to notice contribution may occur because attention is focused elsewhere, either on the initial crisis, symptoms, stigma or an altered/changed identity. The significance of initial focus is highlighted in a recent longitudinal study which suggested that increased stigmatised appraisal of individuals with a diagnosis of schizophrenia was related to poorer long-term outcomes (Markowitz, Angell, & Greenberg, 2011).

There seems to be a similarity between the subjective recognition of contribution in the current research and research which has distinguished between subjective and objective burden. Namely, that subjective appraisal seems to be more heavily influenced by processes rather than empirical events (Raune et al., 2004). A possible explanation for why this occurs is suggested by the data related to expectation. That is if gradual increases in contribution are constantly assimilated, the historical view of

the individual or situation remains unaltered or stuck in a 'illness ideology' (Maddux, 2008).

The interviews suggested that accommodation of information may be initiated when there is a rapid shift in expectation or change becomes the object of attention. The constructed model also suggests that the conceptualisation of the problem and recovery influences the value placed on positives which influences the ability to notice. Specifically, individuals with a stronger problem-focus may find it more difficult to notice positives.

Charmaz's (2002) research with severe physical illness which suggested the self-concept does not change immediately upon diagnosis but instead through a process of iterative feedback, seems to contrast with the current study. The majority of participants indicated there was an immediate change in self-concept following the recognition or labelling of psychotic experiences. While it is possible that individuals experience a far more gradual alteration in the self-concept than suggested in the current interviews, the recognition or creation of a psychosis-as-self aspect nonetheless seems to alter the way in which actions or agency relate to the self-concept. Although all individuals were engaged in regular acts of contribution, the majority of individuals and relatives at the start of the interview reported that the individual was doing little to support their families. The current model therefore contrasts with Coldwell et al's (2010) research which suggested that contribution following psychotic experiences is dependent on changes in identity.

Clinical Implications

That the value or worth of an object is related to the assumptions ascribed to it rather than the object itself is clearly exemplified in Tracey Emin's work 'My Bed'. With a change in assumption, a soiled and detritus-covered bed is transformed from an object of shame to high art. The challenging nature of psychotic experiences, combined with stigma of the label, may mean that it becomes a place-holder for identity (Lally, 1989). If the self and psychosis become synonymous, acts which would normally be ascribed value relative to the self and others may be viewed as irrelevant.

The current findings would suggest that an illness-centric view of the person may be unhelpful for a number of reasons. Only noticing contribution which is consistent with the illness-self may constitute a self-fulfilling prophecy, as individuals, relatives and services wrongly attribute a reduced capacity. This may in turn mean that individual does less because they subjectively appraise things as being beyond their capacity. An illness-centric view may also mean that when contribution is noticed, the agency for the action is attributed outside of the individual. Increased contribution (if noticed) may be framed in relation to improved management of 'symptoms', which thereby may be attributed to the therapist or medication, which is suggested to strengthen the illness self attribution (Maddux, 2008). The current study and Coldwell's et al's (2010) would suggest that simply asking about positive aspects or actions may counteract this perceptual bias. Encouraging a space in therapy to explore positive contribution may therefore have clinical efficacy.

The efficacy of encouraging a more positive relationship to self is suggested in research which has found that there is a supported relationship between the negative

content of hallucinations and delusions and negative self-concepts (Close & Garety, 1998; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001). Additionally, the strength by which psychotic beliefs may be held is also suggested to relate to the fit of the belief with the self-concept (Garety et al., 2001). The importance of recognising the value and worth relating to acts of contribution and ascribing this value to the individuals' agency, from a service perspective is that encouraging a positive self-concept may reduce the strength and content of symptoms.

Growth and positive change following traumatic events are heavily influenced by the degree of perceived control. Research has demonstrated higher rates of growth in individuals who perceive themselves as having a higher internal locus of control over the events, even if this control was illusory (Zoellner & Maercker, 2006). By neglecting personal strength and ability and locating agency outside the individual (family, services) the experience of growth may reduce (Tedeschi & Calhoun, 2004).

Modifying the perception 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 demand in relation to one's belief in that one can meet the demand (self-efficacy). Therefore, if relatives perceive themselves as wholly responsible for their loved one's mental health, they are more likely to appraise this situation as being more demanding or beyond their capacity. Indeed, research suggests that if care-giving is perceived as less emotionally straining then parents are more likely to see their child as supportive. (C. Schwartz & Gidron, 2002). The direction of causality hypothesised in the current model however, would suggest that increased perception of a loved one's supportive

behaviours may lead to decreases in the perceived emotional strain. Reduced strain may thereby reduce the demand on services by relatives (NICE, 2003).

Limitations

The current model was constructed from a sample of individuals who were all white-British, predominantly female and maintained regular contact with either family or partners. As such the model may not fully or accurately represent the experiences of all males or females with FEP, individuals from other ethnicities or who are more socially isolated. The sample may be constrained by a further bias. It is possible that individuals and relatives where contribution is less frequent would be less motivated to take part in such research. However, given that four participants expressed the belief that either they or their family member did not contribute, the sample might not be biased in this regard. Additionally, difficulties with recruitment entailed that theoretical sampling solely involved the modification of interview focus and questions rather than the selection of individuals.

Future research

The current study would suggest that exploring the relationship between recovery and contribution might be a worthy area for further research. There were some indications that recovery type might influence the conceptualisation of contribution and recovery.

The difficulties recruiting and accessing participants for the study may suggest services and staff may experience a similar perceptual bias to the studies participants. Services frequently indicated that they had been unable to recruit potential participants, because the clients in the care-coordinators view simply didn't

contribute to their families. This potential bias could be investigated with research directed at exploring staff and services conceptions of positive contribution in FEP. Lastly, it is believed that research involving a longitudinal design would greatly expand the clarity of processes and change in relation to FEP and contribution.

Conclusion

The constructed theory suggests that while individuals with FEP can and do regularly contribute to their relatives, such contributions may not always be noticed or valued. The model suggests that noticing and valuing contribution may have not only a positive impact on wellbeing but may also encourage continued or increased contribution.

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SECTION C: CRITICAL APPRAISAL

Justin J.P. Allman BA. Hons Psych., BA. Phil., PGDip Stats, PhD

How individuals with first-episode psychosis positively contribute
to their families. A grounded theory analysis

Section C: Critical Appraisal
Word Count: 2000

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

This was my first time using a grounded theory (GT) approach, and I found it a far more challenging process than previous experiences with quantitative or qualitative analyses. I do not feel that GT is a wholly appropriate method for the MRP, specifically due to the constrained timeframe in which projects must be completed. In part this is based on a fear that I reached data ‘saturation’ on pragmatic grounds rather than wholly analytical grounds.

While part of me feels that this arises out of an anxiety that I just haven’t fully understood the research method, another part of me feels that not fully understanding is part of the method. For example modelling the data according to axial coding as in Strauss and Corbin’s (1998) traditional approach felt too prescriptive and against the spirit of the method, though this is obviously something that other researchers have found very useful. On the other hand I was heartened and equally dismayed by Charmaz’s (2006) own accounts of how she has continued to return and expand upon her original data set over the last 40 years. I am very aware that part of my unease about the analysis is a feeling that theories in actuality can never be fully saturated and at best one can only hope for a useful partial theory.

Applying a GT approach has made me far more aware of the lack of questioning of assumptions in the majority of quantitative research. This comes from a greater appreciation of epistemological positioning, and viewing the foundations on which all research is based as pragmatically assigned. While I had originally intended to

attempt analysis without consulting the research field (Glaser & Strauss, 1977), ‘bracketing’ off my preconceptions, I quickly found that this was a largely impossible endeavour, as while intending not to I was constantly making references to the project in my thinking. For example, in an effort to gain a better understanding of Charmaz’s version of GT, I read a number of her articles. These articles happened to focus on identity and illness perceptions, and while I attempted to bracket these associations so as not to let it bias the research, I found it impossible not to relate to the degree of symmetry between my research questions, the initial data and Charmaz’s. In attempting to avoid this I kept a number of reflexive journals, and made use of memoing. In the end I found the memoing far more useful than the initial bracketing, as it allowed me to explore the ‘interesting idea’ (sometimes repeatedly) and then just write afterwards (or before) “this is not the focus of the research question”. Whether this is a correct use of the method, I’m not sure, but my current understanding of GT is that if one attempts to bracket ideas, memos them with an instruction to ignore, and yet returns to them, perhaps these ideas are relevant to the constructed theory.

What I learnt most from the research process is how much I missed in the initial coding (and thereby in communication more generally) and the complexity of meaning that can inhere in even a single sentence.

2. If you were able to do this project again, what would you do differently and why?

I have applied to University ethics boards and primary education committees repeatedly throughout my undergraduate and doctoral research, and have always found this a straightforward and relatively pain-free experience. Indeed, the current

project's initial approval through the University research board was a useful and directive experience. I found the process of learning to use the NHS's Integrated Research Application System (IRAS) which I had to apply through, (despite numerous on-line tutorials and help files), ill-defined and obtuse regarding what information should go where. As a result I spent months learning to write an application, though the actual writing process took no more than a week. However, as the meeting with the Ethics committee was straight-forward, and they commended me on the clarity of my application, I realised that at least part of the difficulty related to my own anxiety. As while the IRAS form didn't make much sense, the ethics committee was aware of this. While I believe I would find further applications less arduous in the future, given a time machine I would have advised myself to avoid NHS ethics if possible.

Unfortunately getting R&D approval was even less straight-forward. Although the trust's R&D office was extremely helpful regarding my R&D application, probably because I had never worked in the trust I was applying to and my original trust supervisor went off on long-term leave, there was an almost never-ending list of checks to be made. Some of which even the R&D staff were unsure how to accomplish, e.g. getting a research passport. All in all the R&D application process from start to finish took over 11 months and despite all the governance and feasibility checks due to difficulties with recruitment I ended up applying to another trust for R&D approval (this process taking only a few phone calls, emails and a couple of hours). I feel that even if I were doing an identical project now, if the application process was not appreciably shorter, I would not apply to the same trust again.

Aside from the difficulties with the application, I think if I were doing this research again I would fundamentally alter the recruitment process. Firstly, I would have tried to pay participants, as a frequent response for why a number of males had elected not to take part in the study was the lack of payment. This option had been discussed in my initial university ethics meeting and application to the trust, both of which suggested that given the vulnerability of the sample payment might be viewed as too compelling and ethically dubious. Secondly I would need to be working in the trust that I am recruiting from. Given that the trust I applied for had a large number of research projects on going, keeping the project alive in the mind of staff required a higher degree of contact than the occasional visit, frequent phone calls and emails. If I had been working at the trust I would also have altered the application to allow me to approach participants directly. This possibility had been rejected as it was felt that it would not be appropriate for me to wait around the EIP services' waiting rooms to recruit participants.

Lastly for the purposes of this write-up given the time constraints I would have used thematic analysis rather than GT, as I found the latter far too demanding and encompassing given the demands of placement and other coursework. In reality though this is probably due to my own inability to let go of things, particularly, accepting a good enough explanation rather than getting tied in knots looking for a perfect explanation.

3. *Clinically, as a consequence of doing this study, would you do anything differently and why?*

Through frequent discussions during team-meetings and personal communications during recruitment I was really struck by the degree of assumed burden. That is,

frequently when talking to care-coordinators about recruiting potential participants, it was explicitly expressed that their clients did not positively contribute to their families and therefore they did not feel comfortable seeking recruitment as it may negatively impact the client. Rather than seeing this as a specific characteristic of the service staff, I feel this is a result of how services are set-up or what Maddux (2008) has called the 'illness ideology' of services. While relating this to the NHS can fill me with a sense of hopelessness, I do feel (perhaps naively) that individual clinicians can make a difference to the mindset of individual teams.

The project highlighted a number of my own biases, for example despite the project's focus, the information sheets and consent forms I created classified relatives and partners as caregivers. My implicit assumption therefore was that individuals who have experienced FEP need to be looked after. Even though I have direct experience that this is not the case, I now realise that resisting bias is a battle of meaning not experience. I would hope in my future clinical work to be more forthright in questioning my own and others assumptions in this regard, specifically by making a point of asking about potential positives in my discussion with staff and during team meetings.

Interestingly, at the start of the interview the majority of the interviewees both relatives and SUs also tended to express the view that the individual with psychotic symptoms was someone who was looked after and didn't contribute that much to their family. The interview schedule, possibly because it focused on specific areas of contribution, seemed to lead to a questioning and frequently a redressing of this assumption. As interviewees frequently indicated that the interview had led to an

increase in well-being, such questions may be usefully applied clinically. I feel that in my future clinical work questions of this nature could be usefully integrated into the initial assessments.

Throughout training I have found it helpful to routinely audio-tape and listen to my sessions. While this has made me aware that I often miss pertinent information during sessions, the process of coding data was forced me to realise how much information I can miss even on a second listening, or a third and fourth reading. This has highlighted to me the absolute need to be more tentative in my assumptions regarding what I feel a person is telling me and what assumptions the individual's telling might be based on.

4. If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

I feel that there a number of areas which would be a worthwhile focus for further study. Firstly, the current study could be extended to include peer-relationships and their perspective on the individual's degree of contribution. One of the difficulties with doing this however relates to the fact that the majority of SU participants in the current study went to great lengths to hide their experiences from their peer-group, suggesting that samples would be selectively biased. Given that the emerging adult research would suggest that individuals may be more influenced by peer attitudes this would nonetheless be a worthwhile areas of research.

Another study which I have thought about pursuing involves carrying out a Foucauldian discourse analysis on existing contribution research. Interestingly, this

methodology was raised in an original meeting with the research board, specifically as the project advocated a social constructionist framework and could be viewed as a response to the dominant burden narrative. However, at the time I felt that GT might be more worthwhile, as the possibility of testing the constructed theory might facilitate greater research interest in the area. I now feel that analysing how language is used in this area of research, may highlight why certain findings and inferences are drawn from the data and not others.

As mentioned above several participants indicated that engaging in the interview led to a changed perception of themselves or their relative, and this was frequently associated with an increased sense of wellbeing. As the previous study by Coldwell et al (2010) indicated a similar finding it is possible that such interviews may have clinical efficacy. This possibility could be tested either using a between-groups RCT type study or a series of single case designs as part of routine client work. The RCT type study would likely involve randomly assigning participants to either an assessment as normal condition or an assessment with contribution questions condition, as part of intake assessments to EIP services. Efficacy could be assessed with the use of standard measures of mood immediately before and after assessment, ideally with follow-up assessment to test if intervention effects are in any way lasting. The single case design would probably best be suited to an IAPT type service, were clients are required to repeatedly fill out psychometric measures as part of routine intervention. As such the introduction of the interview schedule could be assessed against intervention as usual, and depending on where in the intervention the interview was introduced, lasting efficacy could also be assessed.

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Section D:

List of Appendices

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Appendix I Literature search strategy

The literature search strategy consisted of a general search concerning the topic of first episode psychosis and a specific literature search on psychosis, contribution and families.

Search Strategy of General Literature on Psychosis

The following electronic databases were accessed in the search (COCHRANE database of systematic reviews, PsycINFO, Wiley Online Library, Sage Journals online, ScienceDirect, and Web of Knowledge), books and hand searching of bibliographies. The reviews retrieved were predominantly linked to drug interventions. Upon accessing an article in the topic area, its bibliography was scanned to identify other core texts and papers, which informed the general review of contribution within its historical and psychiatric context within the burden literature.

Search Strategy of Literature on Contribution, Families and Psychosis Inclusion criteria.

The review of contribution in psychosis was limited to studies in peer reviewed journals, including both quantitative and qualitative research. As Psychosis is an umbrella term and contribution is a emerging area of research a wide range of variation of the terms were included. Due to the lack of studies addressing first episode psychosis and family contribution, studies in focused predominated on psychosis and contribution were included. The search was limited to articles in the English language only.

Search strategy.

The studies reviewed in this paper were identified through computer-based searches of the following databases: PsycINFO, Wiley Online Library, Sage Journals online, ScienceDirect, and Web of Knowledge (inception to April 2011). Combinations of

search terms using Boolean operators were employed to identify relevant papers; the main focus being 'Psychosis' and 'contribution'. Truncation was used to search for different word stems and endings. Additionally, the reference sections were manually searched and search terms were entered into more online search engines including 'Google Scholar' and 'Google books'.

Psychosis search terms consisted of:

[psychosis], [psychotic], [schizophrenia], [schizoaffective], [schizoid], [delusion], [hallucination], [Bi-polar], [serious mental health], [serious mental illness], [mental health], [mental illness], [PTSD], [dementia], [manic], [depress\$], [madness].

Contribution terms included:

[Contribution], [Contribut\$] [Positive support\$], [support\$], [gratification\$], [gratif\$], [gratifying], [benefit\$], [gain\$], [burden\$], [benefaction], [help], [assistance\$]

Family terms included:

[family], [famil\$], [partner\$], [husband\$], [wife], [wives], [spouse], [parent\$], [relation\$], [relative\$], [sibling\$],

Appendix II Further methodological considerations

Inclusion Criteria

Individuals were included in the possible participant sample if they met the following inclusion criteria:

- 1) they had first episode psychosis as defined by multidisciplinary assessment as per service entry criteria or are a relative or partner of such an individual.
- 2) were currently under the care of the Early Intervention in Psychosis service (EIPs), or a relative of such an individual.
- 3) were deemed stable and not currently in crisis by the EIPs staff team.
- 4) service user participants were aged between 16 and 30 and relative/partner participants must be aged 16 and over.
- 5) were willing to participate in the interviews with the main researcher and have their interview audio-taped
- 6) were able to communicate in English
- 7) were deemed capable of giving informed consent by the EIPs staff team and their care co-ordinator.

Exclusion Criteria

Individuals were excluded from the study under the following criteria if they had:

- 1) excessive, current substance misuse that would interfere with either the ability to fully participate in the interview or the individual's capacity to consent.
- 2) evidence of significant neurological factors or intellectual disability that may impair the individual's capacity to participate in the interview
- 3) assessed using the trusts risk assessment procedures as presenting a significant risk to others.

Further Ethical Considerations

Participants were made fully aware that they are under no obligation to take part in the study and that they were free to withdraw from the project at any point without giving a reason. Participants were assured that the decision to participate or not in the study would in no way affect their current or future care within the EIP or wider care system.

Participants were be informed that anything they share would be anonymised and kept confidential, unless the researcher had cause to believe that there was any risk to the participant or another person, at which point confidentiality would have been broken in accordance with standard clinical practice.

Individuals or family members of individuals who meet the eligibility criteria for the project were approached through the EIP service sites by the staff working directly with the family. This ensured that participation in a research project was entirely voluntary, and that no one is coerced to participate in a research project against his/her will by the researchers.

Only individuals who were been deemed to have functional capacity to consent by their Care coordinator, was be approached concerning participation. Therefore all individuals taking part in the study could:

- 1) understand the information relevant to that decision, including understanding the likely consequences of making or not making the decision;

- 2) retain that information;
- 3) use or weight that information as part of the process of making the decision;
- 4) communicate their decision

Potential Risks of research

It was possible that participants could have become distressed when responding to the interview items. If this had occurred, the researcher would have used their clinical skills to contain the immediate distress, before assessing whether the participant's distress could have been contained or whether the participant's care coordinator needed to be informed. A clear briefing and debriefing was offered before and after completing the interview.

One burden on the participant was travelling to an NHS site and participating in an hour long interview. We hoped to minimise such burdens by reimbursing travel expenses and holding the interview at a site that was local and familiar to the participant. However the majority of participants elected to be interviewed in the participant's home.

Risks to Researcher

A potential risk for the researcher is meeting participants who are not otherwise known to them, on an individual basis. This risk was being minimised by the researcher adhering to the relevant NHS Lone worker policies and protocols. Additionally, when interviewing participants at home the researcher followed the recommendations from the Social Research Association's (n.d) Code of Practice for the Safety of Social Researchers. The researcher also checked with the staff team directly working with the family to ascertain if there was any known risk associated with interviewing the participant at home.

Service User Involvement:

The project consulted with [REDACTED] service user group and [REDACTED]. This consultation shaped the development of the interview schedule, information and frequently asked questions sheets and consent forms.

Recruitment:

On the arranged day participants were asked to read (no-body require assistance) and sign the consent form by the chief investigator. Participants will be reminded that they are free to withdraw from the study at any point, in which case their data will not be used in the analysis.

Mental health Act

If the participant agrees to meet the main researcher, and has capacity to consent in accordance with the Mental Capacity Act code of Practice (sections 30-34) as assessed by the EIPs staff team or their care coordinator, the main researcher will discuss the nature and requirements of the study to ensure informed consent.

Appendix III Information, frequently asked questions sheets

Participant Information Sheet

(This is an information leaflet for you to keep)

Study title: What beliefs are held by individuals who have experienced first episode psychosis and their families about their capacity to make a positive contribution to their families?

Introduction

I would like to invite you to take part in a research study that explores positive contribution in individuals who have experienced first episode psychosis. Before deciding if you wish to take part, it is important that you understand what participation and the research study will involve. If after reading this information sheet you are unclear or would like more information about this study please ask me.

My name is Justin Allman and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. This research study is part of my training, and is supervised by Ms Anne Cooke and [REDACTED] who are both clinical psychologists with extensive experience in working with people who are experiencing mental health difficulties.

What is the study about?

Recent research suggests that individuals with mental health difficulties often contribute in meaningful and novel ways and can be an invaluable source of support for their families. This study is hoping to explore how people who have experienced first episode psychosis positively contribute to their families and to others. The study also hopes to explore how family members of individuals who have recently experienced first episode psychosis think about recovery.

It is hoped that such information may lead in time to improvements in service provision and/or reduced stigma and discrimination for individuals experiencing mental health difficulties. In exploring these issues I am hoping also to interview: people who have recently experienced first episode psychosis and the relatives of people who have recently experienced first episode psychosis.

Frequently Asked Questions

What would the study involve for me?

If you agree to take part in the study, it would involve meeting up for around an hour and taking part in an interview. In the interview I will ask some questions about:

- 1) What things that you value about yourself and what things you believe your family members or others value about you
- 2) what things have made having valued roles easier and what things have made this more difficult,
- 3) what difference you think this makes to your family and others and to how you view yourself, and
- 4) how you think about personal recovery.

In order for me to collect the information accurately, I will audiotape the interview. The interview will then be transcribed afterwards, thereby ensuring that your views are accurately represented.

Do I have to take part?

No, it is up to you to decide if you would like to take part or not. I will describe the study to you and give you this information sheet to keep. You will be given at least 48 hours to decide if you wish to take part. If you wish to take part I will ask you to sign a consent form to show that you have agreed to take part. However, you are free to withdraw from the study at any time without giving reasons or explanations. Withdrawing from the study will not affect the care you receive from the health services or other organisations.

Will my relatives have to take part in the study if I do?

No - while I will be interviewing relatives of individuals who have experienced first episode psychosis, they do not need to be relatives of the individuals who are taking part in the study.

How will the interviews be used?

I will write up the findings from the interviews to create a report for my doctoral qualification, and send a summary of this information to everyone who takes part in the study. In addition I plan to publish these findings in a scientific journal.

Will it be confidential?

All procedures will be taken to protect your identity for example by changing names or identifiable information. The report will be written up to describe the themes that were raised in the interviews, and not about each participant individually. While direct quotations may be used to illustrate issues and themes, any identifiable information will be removed.

The tapes from the interviews will be destroyed once they have been transcribed, with the transcripts containing no personally identifiable information (e.g. all names and identifying information will be changed). In keeping with standard data protection procedure the transcripts will be kept on a password protected CD which will be stored in a locked cabinet at the Dept of Applied psychology campus for a period of ten years before being destroyed. Neither the transcripts of the interviews nor the data

held on CD will have your real name on it. Only myself and my supervisors will have access to the information.

Are there any possible risks of taking part?

There is a small possibility that you may find that talking about some of the issues difficult. For this reason it is a good idea to discuss the ‘pros and cons’ of participating with family, friends or other professionals you are in contact with before deciding to whether you wish to take part in the study. If you are feeling particularly vulnerable at the moment, you may want to wait and take part in the study at a later date, or you may decide not to take part at all.

It is important to note, however, that this study like all research carried out in the NHS has been reviewed by an independent group called a Research Ethics Committee, which is designed to protect your safety, rights, wellbeing and dignity.

Are there any possible benefits of taking part?

While we cannot promise that you will benefit from taking part in the study, the information gathered may lead to a greater understanding for families and clinicians concerning how individuals who have experienced first episode psychosis positively contribute and think about recovery. Some people that have previously taken part in previous studies have reported that they have found such conversations useful in themselves.

Will travel expenses be refunded?

If you have to travel to take part to be interviewed, travel expenses up to a maximum of £10 will be refunded.

What if I have any concerns?

If you have concerns or would like to know more about the study, you can contact me to discuss and I will try my best to answer your questions. If you wish to make a formal complaint, you can do this through the NHS you are in contact with, doing so will not affect the care you receive.

For further information:

If you would like to know more about the study, and/or wish to take part please ring (07810 363113) and leave a message, or email me (ja156@canterbury.ac.uk). I will get back to you as soon as possible. Alternatively, you may prefer to discuss any concerns about taking part in the study with [REDACTED], who is a service user research liaison for the project who has previous experience of psychosis [REDACTED]

Thank you for taking the time to read this.

Participant Information Sheet - Carer
(This is an information leaflet for you to keep)

Study title: What beliefs are held by individuals who have experienced first episode psychosis and their families about their capacity to make a positive contribution to their families?

Introduction

I would like to invite you to take part in a research study that explores the positive contribution of individuals who have experienced first episode psychosis. Before deciding if you wish to take part, it is important that you understand what participation and the research study will involve. If after reading this information sheet you are unclear or would like more information about this study please ask me.

My name is Justin Allman and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. This research study is part of my training, and is supervised by Ms Anne Cooke and [REDACTED] who are both clinical psychologists with extensive experience in working with people who are experiencing mental health difficulties.

What is the study about?

Recent research suggests that individuals with mental health difficulties often contribute in meaningful and novel ways and can be an invaluable source of support for their families. This study is hoping to explore how people who have experienced first episode psychosis positively contribute to their families and to others. The study also hopes to explore how family members of individuals who have recently experienced first episode psychosis think about recovery.

It is hoped that such information may lead in time to improvements in service provision and/or reduced stigma and discrimination for individuals experiencing mental health difficulties. In exploring these issues I am hoping also to interview:

- 1) people who have recently experienced first episode psychosis and
- 2) the relatives of people who have recently experienced first episode psychosis.

Frequently Asked Questions

What would the study involve for me?

If you agree to take part in the study, it would involve meeting up for around an hour and taking part in an interview. In the interview I will ask some questions about:

- 1) What things do you value about your relative and what things you believe your relative your family members or others value about your relative
- 2) what things have made it easier for him/her to contribute and what things have made this more difficult,
- 3) what difference you think this makes to your family/others and how your relative/client views him/herself, and
- 4) how do you think about your relatives personal recovery.

In order for me to collect the information accurately, I will audiotape the interview. The interview will then be transcribed afterwards, thereby ensuring that your views are accurately represented.

Do I have to take part?

No, it is up to you to decide if you would like to take part or not. I will describe the study to you and give you this information sheet to keep. You will be given at least 48 hours to decide if you wish to take part. If you wish to take part I will ask you to sign a consent form to show that you have agreed to take part. However, you are free to withdraw from the study at any time without giving reasons or explanations. Withdrawing from the study will not affect the care you or your relative receives from the health services or other organisations.

Will my relatives have to take part in the study if I do?

No - while I will be interviewing relatives of individuals who have experienced first episode psychosis, they do not need to be relatives of the individuals who are taking part in the study.

How will the interviews be used?

I will write up the findings from the interviews to create a report for my doctoral qualification, and send a summary of this information to everyone who takes part in the study. In addition I plan to publish these findings in a scientific journal.

Will it be confidential?

All procedures will be taken to protect your identity for example by changing names or identifiable information. The report will be written up to describe the themes that were raised in the interviews, and not about each participant individually. While direct quotations may be used to illustrate issues and themes, any identifiable information will be removed.

The tapes from the interviews will be destroyed once they have been transcribed, with the transcripts containing no personally identifiable information (e.g. all names and identifying information will be changed). In keeping with standard data protection procedure the transcripts will be kept on a password protected CD which will be stored in a locked cabinet at the Dept of Applied psychology campus for a period of ten years before being destroyed. Neither the transcripts of the interviews nor the data held on CD will have your real name on it. Only myself and my supervisors will have access to the information.

Are there any possible risks of taking part?

There is a small possibility that you may find that talking about some of the issues difficult. For this reason it is a good idea to discuss the ‘pros and cons’ of participating with family, friends or other professionals you are in contact with before deciding to whether you wish to take part in the study. If you are feeling particularly vulnerable at the moment, you may want to wait and take part in the study at a later date, or you may decide not to take part at all.

It is important to note, however, that this study like all research carried out in the NHS has been reviewed by an independent group called a Research Ethics Committee, which is designed to protect your safety, rights, wellbeing and dignity.

Are there any possible benefits of taking part?

While we cannot promise that you will benefit from taking part in the study, the information gathered may lead to a greater understanding for families and clinicians concerning how individuals who have experienced first episode psychosis positively contribute and think about recovery. Some people that have previously taken part in previous studies have reported that they have found such conversations useful in themselves.

Will travel expenses be refunded?

If you have to travel to take part to be interviewed, travel expenses up to a maximum of £10 will be refunded.

What if I have any concerns?

If you have concerns or would like to know more about the study, you can contact me to discuss and I will try my best to answer your questions. If you wish to make a formal complaint, you can do this through the NHS you are in contact with, doing so will not affect the care you or your relatives receive.

For further information:

If you would like to know more about the study, and/or wish to take part please ring (07810 363113) and leave a message, or email me (ja156@canterbury.ac.uk). I will get back to you as soon as possible. Alternatively, you may prefer to discuss any concerns about taking part in the study with [REDACTED] who is a service user research liaison for the project who has previous experience of psychosis [REDACTED]

Thank you for taking the time to read this.

Appendix IV Consent forms

Consent form

Title: What beliefs are held by individuals who have experienced first episode psychosis and their families about their capacity to make a positive contribution to their families?

Please read the following statements, tick if you agree with the statement and sign and date underneath if you wish to take part in the study.

- 1) I have read and understand the information sheet dated 25 November 2010 and have been given a copy of this to keep.
- 2) The nature, purpose and possible difficulties of taking part in the study have been explained to me and I understand these, I have had the opportunity to ask any questions I may have had.
- 3) I am aware that I am free to withdraw at any time from the study, without explanation, and that this withdrawal in no way will affect my legal rights or the care I receive.
- 4) I understand I have no obligation to participate in the study
- 5) I consent to having the interview tape-recorded
- 6) I consent to the interviews being transcribed.
- 7) I understand that my name and any other identifiable information I provide will be treated as firmly confidential. I understand that when the study is written-up, no identifying information will be contained in the write-up. I understand that extracts of the transcripts may be included in the written report but that it will not be identifiable from these extracts.
- 8) I understand that it is planned to publish this study in a scientific journal.

Name of participant Date Signature

Researcher Date Signature

Appendix V Interview schedules

Interview Schedule: Service Users:

- 1) I was wondering, how do you view your recent unusual experiences?
 - a. Prompts: are these experiences seen as a problem or a source of personal growth?
 - b. If so how have you grown/ what is/are the problems?
- 2) People often contribute to their families in many different ways. I am interested in your opinion of what you give to or how you help your family. Could you tell me the ways you think you do this?
 - a. Prompts: practically (do you help with the house work or preparation of meals), emotionally (are you a shoulder to cry on for others in your family, do you make people laugh/cheer them up, can they rely on you, etc), socially (organise get-togethers or social events in the family) or financially (support the family money-wise)
- 3) What things if any do you think have enabled/helped make it easier for you to have these valued roles?
 - a. Prompts situations (e.g. work or not being in work/ availability, new opportunities, prior family relationships); Own characteristics (e.g. skills, severity of symptoms, relative's characteristics; expectancies (ie what other people expect of you or what you expect of yourself)
 - b. Has the way you have contributed changed over time?
 - c. are there other ways that you think you could contribute?
 - d. What things, if any, have made it harder for you to contribute?
 - e. If you did not contribute in this way, what effect would that have on the family?
- 4) How would (Y) (a close relative) describe how you contribute?
- 5) Do you think that having these unusual experiences has enabled you to contribute in ways you didn't before?
 - a. Has it enabled you to get back a role you used to have before?
 - b. Has it made you more creative/spiritual/given you a better sense of humour etc?
 - c. Do you think other people in your family will have noticed these benefits?
- 6) Has your relationships with members of your family changed since you first experienced these problems/unusual symptoms?
 - a. How about between different members of your family?
- 7) How do you view recovery?
- 8) Is there anything else you think is important about this topic that we haven't covered?
- 9) How have you found answering these questions?

**Interview Schedule:
Carers:**

- 1) I was wondering, how do you view your relative's recent unusual experiences?
 - a. Prompts: are these experiences seen as a problem or a source of personal growth?
 - b. If so how have they grown/ what is/are the problems?
- 2) People often contribute to their families in many different ways. I am interested in your opinion of what X gives to or how X helps your family. Could you tell me the ways you think X does this?
 - a. Prompts: practically (do they help with the house work or preparation of meals), emotionally (are they a shoulder to cry on for others in your family, do they make people laugh/cheer others up, do others rely on them for support, etc), socially (do they organise get-togethers or social events in the family) or financially (do they support the family money-wise)
- 3) What things if any do you think have enabled/helped make it easier for X to contribute?
 - a. Prompts situations (e.g. work or not being in work/ availability, new opportunities, prior family relationships); Own characteristics (e.g. skills, severity of symptoms, relative's characteristics; expectancies (ie what other people expect of them or what they expect of themselves)
 - b. Has the way they have contributed changed over time?
 - c. are there other ways that you think they could contribute?
 - d. What things, if any, have made it harder for them to contribute?
 - e. If X did not contribute in this way, what effect would that have on the family?
- 4) How would (X) describe how they contribute?
- 5) Do you think that having these unusual experiences has enabled X to contribute in ways they didn't before?
 - a. Has it enabled X to get back a role they used to have before?
 - b. Has it made them more creative/spiritual/given them a better sense of humour etc?
 - c. Do you think other people in your family will have noticed these benefits?
- 6) Has your relationships with members of your family changed since X first experienced these problems/unusual symptoms?
 - a. How about your relationship with X?
- 7) How do you view recovery?
- 8) Is there anything else you think is important about this topic that we haven't covered?
- 9) How have you found answering these questions?

Appendix VI Abridged research diary and journal

08.12.09

Supervisor gave feedback on the IRP proposal- I need to be a little bit more focused on what I'm looking for in the research. Think looking at FEP is the way to go.

13.11.09

IRP proposal submitted

14.12.09

IRP proposal has passed. A few minor corrections. I've been thinking about [REDACTED] suggestion to use discourse analysis. From the little I've read it seems really interesting but I still think GT is the way to go. She also suggested a book by Sue Love called 'Psychosis in the Family'. It is a personal account by [REDACTED] as the mother of a young man who experienced psychosis. I'll try and get it as it might be relevant.

18.12.09

Emailed [REDACTED] to ask for the go ahead to start applying for NHS and Ethic approval

28.1.10

[REDACTED] has given me the go ahead to start the process of applying for NHS ethics and R&D. She was hopeful that the study might produce some interesting findings, and is keen to tie the study into a project she has which is looking for funding ATM. Her study focuses on the remission versus recovery. I guess that contribution and recovery are likely to heavily overlap, will need to include another subject area though ☹ She has also recommended contacting a SU researcher from the trust, which will hopefully help with focusing the project.

5.2.10

Been in contact with [REDACTED] - her suggestions have been really helpful and she seemed really motivated about the project. She suggested that social constructionist GT might indeed be better suited to the study given the emphasis on lived experiences. I guess I'll have to read up on that now too. I'm lifted by the enthusiasm, but it's hard to focus with all the other deadlines and getting up to speed with my client work.

15.3.10

research questions?

What beliefs do individuals who have experienced first episode psychosis and their relatives hold about their capacity to positively contribute to their families?

And one secondary question:

What helps or hinders the opportunity to contribute?

15.5.10 We met up for the first GT support group meeting today, it was nice to realise that I'm not the only one who is struggling to grasp GT

24.5.10

Set-up my IRAS account today, have spent the last four hours looking at a video and reading help files, its not exactly what you would call clear. I'm not sure if I should name a project as I don't think you can change anything once it is written, which is bloody crazy. STRESS

4.6.10

■■■■ has agreed to consult with project, ■■■■ has indicated that she would be willing to give the ethics and R&D proposal a once over before I submit it. I still can't get my head round the Bloody IRAS form.

15.6.10

Finally got a response from ■■■■ about meeting up today but she arranged it for the same time that I said I'm meeting ■■■■, its annoying but hopefully we can rearrange. However the meeting with ■■■■ went really well, she suggested lots of helpful things for the project. She suggested splitting the information sheets into general information and a FAQ sheet which I think might clear things up and make the 5 pages less intimidating. Oh and she suggested cutting the content in half. I said I'd rework it and get it back to her by next week so she can run it by the service user group so they can recommend any further changes. The group also have agreed to go through the interview schedule at the same time.

29.6.10

Why is the bloody IRAS form so obtuse, the questions either seem to be asking the same thing or god only knows what information they are actually requesting! I'm starting to feel really disheartened about the application process, as I was hoping to do the old fashioned GT were I don't consult the research field till after the data has been collected. But it seems that to get ethical approval and R&D I'll need to support every aspect of the research.

21.7.10

Was meant to meet with ■■■■ today but she was of ill. I'm still struggling away with NHS R&D and Ethics forms. And worst of all it looks like I might have to use an alternative sampling method as the bigger project I was meant to tag on to didn't get funding, I'm trying to work this out with ■■■■. ■■■■ Still hasn't been able to get back to me with the SU groups feedback as they weren't able to look things over at the last meeting. Everything in the project seems to have suddenly fallen into paralysis.

12.8.10

How can something be so bloody complicated? I've finally got a working version of the Ethics and R&D and I can't work out how to print the thing. It keeps printing a blank document and the document I save is blank, yet I can still read the information online. I'll ask ■■■■ how to transfer it I think.

26.8.10

■■■■ indicated that because I've never worked for the trust I'll have to get a research passport before they could OK R&D. I've contact Salomons and no body seems to

know anything about it, or have suggested that I don't actually need a research passport. I will try and clear this up with [REDACTED] tomorrow.

7.9.10

So I definitely need a research passport according to [REDACTED], and before I can get SSI I need to confirm with all the teams that they are willing to support the project. After this I have to apply for governance approval, and all this before I even apply to R&D! How many months is this now, I feel so removed from the project I can barely remember what it is about or why I'm interested in it. Can one bracket boredom? Bracket a lack of interest caused by bureaucracy or a belief that one is never going to get approval?

20.9.10

[REDACTED] is going to look at the correct drafts as [REDACTED] is away. I'm not sure why this application process feels so different to other processes. I think it's the lack of clarity, and the fact that the response could just stop the project dead, even after so many months work... don't know what I will do if that happens.

6.10.10

[REDACTED] has agreed to step in and help with recruitment as [REDACTED] is definitely not likely to return to work in the near future. [REDACTED] has also made some good suggestions in regard to crossing the final T's for the R&D application.

7.10.10

Had to correct the R&D form again, when does this end?

13.10.10

[REDACTED] confirmed that I don't need a research passport, but yet I still do! Have tried again to get Surrey and Borders to respond to this but I just keep getting passed around. No-body seems to know how one gets one of these.

29.10.10

Reading [REDACTED] IRP really not sure if it will be directly related to my project but who knows. Feeling a bit more motivated, first time in ages I've been reading something for the project and it hasn't felt like a chore.

24.11.10

Was really nervous going to the Ethics Board. The meeting went really well, they have given it the go ahead, and I will need to confirm once I have received R&D approval. The committee were actually really nice and really approachable so different from the IRAS form process. At least that bit is over now, all I have to do is get R&D approval. And no I haven't been able to get a research passport yet.

15.12.10

As I still hadn't heard back from R&D, called at it seems that the project might have got mis-filed somewhere, so the long and the short of it is I will have to send them another copy. More delay, more stress

30.12.10

R&D approval granted whoot

10.2.11

Still only 2 participants, I'm really worried this project just isn't going to happen. What's plan B? Have talked to [REDACTED] about the possibility of doing discourse analysis on the 2 interviews rather than GT if I can't recruit any one else, but she doesn't think it would be a sufficient project. Why did I go through NHS ethics, why did I choose a project where I can't approach participants myself. Are the staff teams even approaching participants, as they don't seem motivated at all? What was the point of all those governance checks?

24.2.11

Now have R&D and ethical approval to start researching in [REDACTED]

1.3.11 Learning to use NVIVO, I think it really helps, even transferring the codes from paper format was really quick. Not sure I'm being analytical enough, or if I'm looking too deeply at the data. I'm not sure this was the correct methodology for me, I'm just seeing endless connections, and am finding it really difficult not to get drawn towards the other interesting bits that aren't really the focus of the research. Maybe bracketing requires more discipline?

23.3.10

Complete turnaround I have 15 participants. I am shattered but I think that is data saturation or at least practical saturation. I'm worried that I may have bitten off more than I can chew. The interviews have really brought home why this research is important. I'm really struck with potential efficacy of using the interview schedule for intervention purposes. I hope I can do this justice.

Appendix VII Sample memos

Recovery depends on symptoms

So do you in this case view recovery as possible, if you still have symptoms? Or do you think it's not really related to symptoms?

R: No it's not really related to... well, no. I don't know really. I think it kind of is related to the symptoms actually because obviously if I didn't have them and they were in there... I wouldn't be able to understand 'em and then I wouldn't be able to be stronger. So I guess it is kind of related to the symptoms.

The participant seemed to be suggesting that without symptoms, recovery was unlikely to ever take place. While I didn't quite get the point she was making during the interview, what she seemed to be suggesting, is that the symptoms are not what is to be recovered from, instead they prompt a person to seek recovery, which she linked to getting stronger and being more vocal. I couldn't help thinking about how 'curing symptoms' may in this way prevent recovery.

This made me think of giving someone a pill to cure hunger without nourishing the body. Such a pill may increase productivity in the short term, as they would be less "distracted by hunger pangs" but would nevertheless kill the person in the longer term.

Recovery is therefore seeking enrichment or nourishment in life, it is not seeking never to be hungry again. Is recovery seeking what nourishes best? Not sure this is totally on topic.

Coding depth

When I went to code ██████ for some reason I had an overwhelming feeling that it was a really really short interview. The actual interview was just over 1 hour and 15 minutes. Initially I thought that this might of being me trying to motivate myself to just sit down and code the beast, but once I started coding I became aware that ██████ very seldom expressed anything directly, there seemed to be such uncertainty in his expression that the interview almost felt content-less and I got a very strong sense of silent judgement. However, with each sweep of coding I found that there was indeed a high degree empathy and the struggling expression seemed to be some kind of defence against letting himself truly believe that the worst was over, as that might leave him unprepared if difficulties arose again in the future, which was how he found himself in the initial crisis. The problem is that this sentiment is not in any single line or paragraph, which I can code and justify my hypothesis, and it was something that I largely didn't pick up on during the interview, so I didn't pursue it as it only became apparent to me during the later stages of coding... might be a future area of research though?

“Not constructive”

While this struck me as a potentially very powerful positive reframe relating to the experiences at the time, when I re-read the passage was I struck with a sense that either culturally or socially, what Individual seemed to be conveying was that it wasn't good enough to simply withstand de-construction, for an experience to be positive it needed to be constructive, to create or add to the person. I think I need to read more about post-traumatic growth... is what Individual is saying is that in

psychosis resilience isn't good enough, to be good enough one has to grow to survive?

Who notices what

It seems that in some ways the symptoms or the difficulties generally lead someone to stop doing what they are doing for a time. Maybe this is an indirect way of asking others to notice how much they do for others or the effect that they have on others in all kinds of ways. Maybe psychosis is like a pause button, where people can stop and consider life choices, roles expectancies, and possibly even be freed from some of these!

Ultimately, the experience seems to ask questions about value, about place, about meaning in ones life... maybe one can take one's self for granted? When does a dirty pebble become a priceless gem or a blood diamond?

There seems to be something important about whether people notice that there has been a pause button experience or not. If it is noticed people can use the space to think about, make sense or just wonder about the experiences that have come before (or that will come later). Actually wondering how did I get here, where do I want to go next... do I have a choice etc. Using the pause in this way could possibly enrich what comes next. Either by just noticing, taking note of life, relationships, meaning, one can start to build a much richer story. This wondering "what might happen next" or "wondering how one got here" if it is linked to a sense of agency or possibility of choice, change or preference, may allow one to work towards a different life story, were one is not so disempowered, neglected or abused.

It is about engaging in one's story not just watching it.

This pause button metaphor is really compelling to explore but it is not what the research question is about. I need to be more focused, or this project is gonna get really out of hand. Be cruel if it is good you'll come back to it

Storying the interview

I found it difficult at times during this interview to know whether to push for a response or not with Individual. At times I was unsure if she had understood questions as she didn't seem to actually respond to what had been asked but skirt around the topic. I was aware that this might be a defensive position and that she might be guarding against going towards ideas or experiences she didn't want to explore. I regret not scratching the surface more, but I have to be mindful to not to push too hard in the next interview because of this regret. In part this regret is also based on the interview with individual's mum Relative, who tended to place a negative slant even when talking about positives, as in nothing was positive enough, it always required more. Individual's responses seemed to mirror this sentiment, in that she saw knew that that there were positives but neglected the value or had been told too often that these things are worthless?

I think I'm being unfair here, I think I'm just having a very strong response to Relative' stigma endorsement. There is something here about actively endorsing negative stereotypes and not noticing. It seems that if Relative can fail to see the

winning argument against the stereotype, despite its platter presentation, then she probably assumes there is no point even arguing against it?

Supported to do more

I think this idea of faith in one's self or others having faith in one's ability is crucial to becoming more active and engaging in more activities. This in part is captured in other statements about contribution coming from person characteristics... This seems to assume in part a belief that "well of course they are doing that, it is part of who they are". Underlying both seems to be a belief that I can do or should be doing this particular thing, which when recognised and supported by others becomes more established. This may also be a trap though, in that if it is expected of a person and they do not want to continue this role or it is too difficult it may cause problems. Acts are not based on just the ability to do the thing but the sense of self itself.

"Not let her know it affects the way you think about her"

I missed this the first time round. Even though she is talking from a perspective of being informed and people going to her from advice, the assumption is that people are hiding what they really think from her. It is sad that someone that is doing so much can think so little of themselves. Acts do not make the person, being valued does. Its all attachment when you boil down to it isn't it?

Seeing the psychosis

■ seems to be talking about her own process in way, fears about what she might have thought in the past or what she occasionally finds herself thinking, and this anger of judgement is projected into society and a wish to change their views with a new name that would make them be more understanding about these experiences. It is telling that throughout the interview she talked about her son and husbands lack of understanding and withdrawal and their active dislike of daughter. It is almost a belief that if the name changed their reactions might change to???

"I had that myself, you know, when they told me it was psychosis, the shock and the fear was 'Oh my God.' When they said she was on anti-psychotics, that really scared me, because it really made me feel as if she was mad, you know, she was going to be violent... that was my first thought. And I didn't want to tell anybody."

"It's what people think. It's definitely what people think. She is embarrassed. You know, she came over today simply because she wasn't sleeping and she said to me, 'I'm not sleeping and I'm going to be a nutter again,' because you know, she has to lighten it. She actually said to me, 'I can't believe that when I don't sleep it can make me go mad again,' so she worries about it. And I think the biggest thing for her is being judged, is really being judged, and the view that people hold of psychosis. You watch Eastenders, and I've watched it recently and there was a remark where somebody said 'oh, she's psychotic.' And I sat there thinking, they're really portraying that so badly, and that's what gives people the view that psychotic people are mad, violent, crazy... that they can't live normal lives when actually they can, and they can live normal lives and still be caring, and still be kind. But people don't... I just think people are scared of the word and I wish it could be changed to be honest with you."

Recovery versus symptoms

It seems that recovery for some participants doesn't seem to directly relate to the existence or absence or any state of symptomology, but is seen as an entirely different entity. Instead some participants seem to be saying is that recovery relates to a state of being where one is making sense of ones life, and making changes that are in a positive, but this is a process that is not directly related to the existence of symptoms or lack there of. Symptoms in this way can indicate the start of the recovery process rather than something to be overcome or controlled per se. Reminding me of the recovery literature,

Just finished coding of [REDACTED] transcript:

Been thinking that symptoms might be seen as a first stage in noticing that one should move towards recovery, but if one sees recovery as the process of getting rid of symptoms may be neglecting what one needs to recovery from. The symptoms are a messenger not the message.

Symptoms however might be seen as a first stage in noticing that one should move towards recovery, but if one sees recovery as the process of getting rid of symptoms, one may be neglecting what one needs to recovering from. The symptoms are a messenger not the message.

If looking at experiences or making sense of things is associated with sadness and loss as is the case with Individual, they are obviously less likely to engage in this endeavour and therefore may not reach a point of being able to free or and least notice some of the negative actions or roles they find themselves in. This is not just about becoming some for of super human, but about becoming a rounded being with positives and negatives combined, but most importantly its about connecting to a sense of agency which is both empowering and realistic: see Individual's coded for awareness making and Individual:

"Whereas now, because of being all understanding of it and actually controlling it, I now am able to live here on my own and not worry about myself and not feel threatened or anything like that."

The making sense or freeing oneself may therefore have a positive effect on the symptoms or experiences, and one feels empowered, or connects to a sense of agency through resisting the experiences which one may have had difficulty connecting to in the world?

When the Mind refuses to play along

"I feel like I... I can... I just know a lot more about human beings and I know a lot more about what can be very, very, very bad and what can be very, very good. And the power that your mind has on you beyond what you could possibly think of, until it comes along and it stops working you have no idea how important it is. And I think it's helped me grow, in the way I come across and the way I talk to people and the way I just think and I'm very, very aware that my mind doesn't work the same way that other people's does. And I think that's just a learning curve in itself."

"When the world goes mad, one must accept madness as sanity; since sanity is, in the last analysis, nothing but the madness on which the whole world happens to agree."
George Bernard Shaw

This statement really made me think of a veil of existence. That is between the positions of truth and reality lies madness. One can see the world as it exists or play along with reality (the populist view of the world) but if one tries to pair these things together one is mad, and noticed not only that the emperor has no clothes but that he lacks the qualifications to rule as well. In the veil one may be freed up to see things in a new way but be crushed by the enormity of what this means to ones view of self, the world and other people.

This at its heart is the difference between seeing things from another perspective and seeing things how we are expected, supposed to see them. Sometimes it is just easier to play along because noticing the lack of clothes is just too challenging. This seems to be what is going on with not noticing acts of contribution, there is something that simply says 'nothing to see here folks move along'.

Is it that the unreality of the experiences that are so challenging or almost inviting others to stop playing along too. "Linked to node "real to loved one but not to anyone else" or losing someone to the other side of the veil.

This reminds me of Irish mythology and the land beneath the hill. The fairy folk could grant both great treasures and awful horrors, but one never truly knows which has been granted even after the granting!

■ "Yes. Be more realistic rather than all this sort of... cause I think society at the moment is so artificial, I mean it doesn't allow people to be... I say the fact that sort of like, although there's discrim... anti-discrimination laws that in the workplace I think it's very difficult to admit that you do have these problems. And people are meant to be perfect rather than to show any vulnerability."

the experience may therefore open up ones eyes to the frightening vulnerability of being, and being reminded of this vulnerability may be almost intolerable.

this also relates to being in time, and how one exists in the world

P1: There was no future and then eventually after time, you just think, you know hang on a minute, there's still gonna be a tomorrow. There's still gonna be a next week, hopefully.

I: Yeah [laughs].

R: [Laughs]. There's still gonna be another month, another year, another ten years and in time you just sort of think, you know okay, I'm gonna deal with there's gonna be a tomorrow. I'm gonna deal with there's gonna be a next week. You know I'm gonna take things as they are, day by day and then as you get better you start thinking, hey, you know maybe I'll do this next week and as it goes on it's like, I'm gonna do this next year. And eventually it's like... it's not a dead end anymore. It's like a whole new avenue's opened up all over again.

Appendix VIII Excepts of transcripts showing initial coding

This has been removed from the electronic copy.

Appendix IX Summary of codes from constructed model

Meta-categories	Categories	Subcategories	Abridged codes summary
Contribution	Nature of contribution	Practical support	<p><i>I do the housework with my mum, every day. Either when I come home from my volunteer job or on my days off. And then I sometimes cook dinner. But yeah, I help around the house a lot and do a lot of sewing and craft things.</i></p> <p><i>She always calls me her DIY friend because I'm always the one that she'll turn to, that will actually sort of fix everything for her or help her.</i></p>
		Emotional support	<p><i>So [relative] knows everything about that, and 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. And just the efforts that she makes, make you know you're loved. She goes to a lot of effort to let you know that you, yourself, are valued and loved.</i></p> <p><i>from my brother's point of view, he'd say that I was supportive to him and I helped him do his homework, and I helped him do his things for him... I was like a shoulder to lean on, things like that you know.</i></p>
		Family enhancement	<p><i>And instead of just being an hour, which it was meant to be for, they actually were there the whole day. They missed out on a dinner that they were going to with her family. And it was a massive turning point in our whole family's relationship.</i></p> <p><i>Well I think her personality and the way that she has been so resilient and got through all these difficulties... is sort of something that is very... very optimistic, makes you feel that as a family we can cope with difficulties when they do arise, even if there are severe difficulties. You know, other people who haven't been through something quite as severe as this, don't quite know</i></p>

			<i>how they would cope with it. But we know, we've actually been through something extreme and come through it.</i>
		Personal enhancement	<i>But definitely the fact that [relative] done it has given him [relative's brother] that extra... incentive to do it. And I say, and it is the fact that he's got the support of her to ask, which I find very valuable.</i> <i>yeah, a source of growth if you like. It certainly enlightened me into things that I'd never experienced before. Perhaps a little bit more conscious of people's emotions and things perhaps.</i>
		Reciprocal exchange	<i>Yes. I've always got a feeling that they can rely on me and if I let them down, they're not going to want to rely on me more, so... I try to be a good friend</i> <i>even though I give them emotional support they give it back to me.</i> <i>Well I suppose she's there for support and she does motivate me to do things when I should be doing them things like college work and stuff. She'll point out if I haven't done something that I need to do. Because I can be kind of... I can be very motivated but at the same time I can forget to do a lot of things, and she kind of helps me remember to do things, and on time. She kind of keeps me together I suppose.</i>
	Self-concept	Self-as-process	<i>But she always had this desire, like even when she was extremely ill she was making appointments at university and getting places, even though she'd given up one university place, which we'd actually encouraged her to do because we felt it was too much for her.</i> <i>[relative's] a very caring person, very caring person. And I think that's her</i>

			<p><i>main attribute really.</i></p> <p><i>Honestly, I just think it's in her nature and I don't think there's anything more to it than that to be honest.</i></p>
		Psychosis-as-self	<p><i>The name doesn't help. It's psycho, cause that's the only thing people hear is that... and when I got told I just thought I'm a psycho. Psycho, psycho, psycho, and you just think of someone that goes killing people and...does crazy things... Well I thought they'd got it completely wrong... I thought I'm sicker than I thought I was.</i></p> <p><i>You know, when they told me it was psychosis, the shock and the fear was 'Oh my God.' When they said she was on anti-psychotics, that really scared me, because it really made me feel as if she was mad, you know, she was going to be violent... that was my first thought. And I didn't want to tell anybody.</i></p> <p><i>I don't know who I was and I don't know which part of that is me and which part of that is... is psychosis.</i></p>
		Growth-in self	<p><i>Well I just think if I can get through, and that and having them horrible experiences every day all day then I can do anything really. (Individual)</i></p> <p><i>Well I think that, you know, with teenagers you just know you're going to experience all these different things and you never know when they're teenagers. But now she's out of the teenage years [laughs], you know, she's [age] so... yeah I'd say it'd be more of a problem.</i></p> <p><i>I think she's realised that actually she can grow-up and can be a normal teenager and have relationships, rather than thinking no one's every going to want to be with me, I'm mad.</i></p>

		A normal-self	<p><i>because as soon as I look upset someone automatically thinks 'Oh my gosh, she's going to go and kill herself.' So I can't have a day where I'm just a bit down because they automatically worry. Like before, they'll be like 'ah she's a teenager.</i></p> <p><i>Yeah. I'd rather be treated as if I was normal because if they treat me like I'm normal, I'll act like I'm normal [laughs]. If they treat me like a sympathy case I'll go round feeling sorry for myself.</i></p> <p><i>Sometimes, because obviously it affects my friendships at college because I have to lie to them and they know I'm lying to them about where I am every week. And cause I can't just say and be upfront about where I'm actually going, they just think that I'm just being a cow and lying to them, but I can't.</i></p>
Impact of psychosis	Problem conceptualisation		<p><i>I suppose in a way, it was not good or bad, because although it was bad at the time and hard to deal with, I did learn something from it and I suppose that is probably maybe a useful lesson to have learnt how to control your anger. And not to belittle people by it.</i></p> <p><i>If someone says something detrimental against mental health, instead of being like I'd want to report them, I'd rather sit down with them and just say 'look, don't say that,' and then teach them not to say it. Cause at the end of the day it's just a case of them learning.</i></p> <p><i>And I think it's helped me grow, in the way I come across and the way I talk to people and the way I just think and I'm very, very aware that my mind doesn't work the same way that other people's does. And I think that's just a learning curve in itself.</i></p> <p><i>Well I don't understand it fully. I mean all I understand is that, you know it is a chemical issue and they're given a different medication for it and it</i></p>

			<p><i>seems to be sorting it out and... Yeah, hopefully that'll be the end of it.</i></p> <p><i>Well post-traumatic stress disorder wasn't diagnosed until... about five months after the psychosis was diagnosed. So that helped me to understand a bit more... and I felt a bit relieved because there was a reason, you know, there was a reason for the psychosis. Whereas when they said 'oh she's got psychosis depression,' you're left thinking well why? What causes it? Why did it happen?</i></p>
	Recovery		<p><i>Well again I suppose it's gradual... as I say at the stage when she's really ill you sort of give up hope in a way, you think that it's never going to get better. And so bit-by-bit you start to see her taking on things</i></p> <p><i>I'm feeling a lot happier in myself... I didn't realise how much it was affecting me, cause when I was doing the [Job] before, I kind of thought this isn't what I want to do but just enjoy it for the moment because it's easy. And so you just look at the good things while you're doing it but then when I did get this job and now that I'm doing well at it, I kind of like a weight's been lifted... and you don't realise</i></p> <p><i>And I suppose she is gaining from that and realising kind of how far she's come since she started all things like the new medication and stuff. Because she was quite reluctant to take all that to start with, which I suppose most people are. And they have had some kind of quite bad side affects. But on the whole I think they've been a very positive move</i></p> <p><i>And now I've become more outgoing, back to like what I was before. I don't know if that's down to the medication or just having... that I needed to have that episode to get back.</i></p>
	Stigma		<p><i>So it does prove that just because some people are ill, it doesn't mean that</i></p>

			<p><i>they're useless and need to be locked away kind of thing and that is... that's what... that's just... just knowing that makes me feel good just think that. You know, there are other people and we are still... they're the things I just... I really don't like it and people... but then I would be like it, I think you're weird.</i></p> <p><i>it would make me feel sorry for somebody if they had explained that, because I think that must be something horrible but then I don't know, I still think that people would be a bit like... not really sure about you.</i></p> <p><i>And I worked there for like a year and a half and they were all fine to me, I did get the odd comment made, but I don't know if it was in jest or not, I don't know if it was just me interpreting it wrong. Or... I did have one point where my Manager, they were asking everyone's opinion and he'd said in front of me 'Don't ask [name] because she's crazy,' and then no one asked me my opinion.</i></p> <p><i>I don't understand it. There isn't much help really. And it's just a weird feeling cause you're... it's quite lonely because you don't ever hear about, no one goes round and says 'oh, oh I've got psychosis,'</i></p> <p><i>once it's become less raw and probably less frightening and you know more about it, I think in my eyes, when I knew more about it, it just helped me move on. Accept it. Accepting was probably one of the hardest things. Accepting what happened. Accepting what it was all about.</i></p>
Opportunity	Managing difficulties		<p><i>I've been able to contribute because the voices weren't controlling me enough to hide away, so I was able to go look after my Nan.</i></p> <p><i>Well, definitely through my sort of mental problems, it makes it hard to trust somebody and sometimes hard to be loyal to somebody and emm... because</i></p>

		<p><i>obviously things get twisted and sometimes turn completely against you.</i></p> <p><i>the voices, cause I was constantly being told how worthless I was. So that's why. And then as soon as I told someone about them, and then got them under control and everything with the tablets and people helping, it seems to be much better. But for being told two years that you're worthless, you didn't mean anything, nobody loved you and that... it's quite hard.</i></p> <p><i>before, sometimes when it was the voices, when they were good voices I would... it would drag me out of being depressed. But now I understand that the voices are part of me, it helps me even more because it means like, when I do start feeling sad, when I'd like think about something, it is my own thoughts now. It's not someone else that I think that's talking to me.</i></p> <p><i>She just didn't have the ability to paint, and one of the other problems she got with her new medication was hand tremors. So obviously with painting that's really not a good thing.</i></p>
	Perceived ability to cope	<p><i>I gave her a bit of rope, because I had to. If she'd hung herself, I know it's the wrong thing to say, but that was the way I looked at it. I had to, because I couldn't have wrapped her up in cotton wool for the rest of her life.</i></p> <p><i>And initially that was really difficult, she wasn't, so I was doing it all for her. Then it got to the point where we were dealing with things together, now it's got to the point where she's doing [description of independent activities and roles] These are things I never could have hoped for... ever.</i></p> <p><i>But I think that was something her CPN, quite quickly in the beginning... I don't remember her ever sitting me down and saying '[Relative], you've got to give her some rope,' but I knew that's where she was going with it. I knew that yes, it wasn't going to be healthy for her, wouldn't be for me, but it</i></p>

		<p>wouldn't be healthy for her, to be so reliant on my time and on me. She'd got to be able to grow herself.</p>
	<p>Expectation</p>	<p><i>But... yeah, it's going to be a very long process, and I know she's definitely not ready to kind of do anything, even reducing the Ciprolax. And we're just kind of hoping to, obviously after college would be better as well because some of the pressures from that will be gone</i></p> <p><i>Are you saying did we have high expectations of her? We might have done. Well I think this is the trouble, it's a progressive thing as you go through starting right the way through primary school and all the rest of it, as you go in it's a progression, and of course therefore, you know, when they... she gets to A' levels and you think well, you know, everybody goes to university so go to university. But... there was no sort of exploitation because nobody in our family's ever been an [profession] or anything like that. And... I think in a sense it could have just been as much her own view that she wanted to do that sort of thing, because she doesn't review as... think of... I mean I'd have been quite happy if she'd done something in [other profession] or something like that. But then she'd only view that as being fairly boring and all sort of uncreative and all sorts of things like that</i></p> <p><i>and I think if maybe somebody else might have rung me, like my sister-in-law, I most probably would have told her. But because [individual] had rung me first, I told her.</i></p> <p><i>I guess what did you take from that?</i></p> <p><i>That she can handle it.</i></p> <p><i>it's a problem as I struggled working with it. Like I can't keep down a job</i></p>

			<p><i>for very long cause obviously stress, and it's triggered by stress.</i></p> <p><i>he wouldn't be able to do the things, because he's got so much else on his mind he wouldn't be able to do... to do the simple tasks. You know, he does... he does struggle with that.</i></p>
Noticing	Perceptual bias	Negative bias	<p><i>cause I never really thought about the relationship between me and what I actually contribute. I mostly thought about what other people contribute to me, which is a lot.</i></p> <p><i>Yeah and it's funny, because when I read your form, I read it and I was really worried because it said what positive effects does [relative] have? And I thought oh my God, she's got psychosis, cause when I spoke to you I said 'what... I don't know that there is anything positive,' and then I thought about it and actually there is a lot that I didn't really appreciate that is positive.</i></p> <p><i>Because you get stuck in that negative thinking that psychosis is something, you know, you should hide, not talk about and... I'm always trying to tell [relative]... You see, the thing is, I think I've been so caught up in trying to make [relative] feel positive by saying to her 'well you've done this and you've done that,' that I've not actually thought about it myself. And you know, the positive effect that she has on the family... and she does.</i></p>
		Focusing elsewhere	<p><i>it [interview] helps you get a better understanding of it. It just solidifies it and also makes you feel better cause like going through all this stuff now makes me realise how much I do still contribute and how much I've got better, back to what I was before. More than I would have normally... cause normally in everyday life you don't question it as much and you don't sit</i></p>

			<p><i>back and reflect on it, you just get on with it.</i></p> <p><i>It's probably cause you don't think about it in that much depth in everyday life.</i></p> <p><i>When I think of recovery the first thing that comes to my head is relapse as well. Because I get really scared that I'll think... I get so scared of having a relapse because I just can't imagine going back when I've come so far forward. It just makes me feel really sad. But I don't want to say 'oh I'm in recovery,' or 'I've recovered,' because then I feel like I'm going to jinx myself and everything's going to go back.</i></p> <p><i>I mean, the one thing that... you know I think what worries us is that, you know she seems to be sort of happy now, but you know we're I think always gonna worry that she'll take a dip again. But you know I guess that's probably always gonna be there now to be honest.</i></p> <p><i>the worry I think. That's what I think about.</i></p>
		Emotional betrayal	<p><i>But then, cause whenever I think of it I just think how it's ruined my life, I don't think that it's done any good. So it's really hard to think of the good stuff, I'm sure there is. And actually, actually 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</i></p>
	Relationships, and context	Communication	<p><i>Just basically yet again, communicating with her. If I knew it was getting too much for her then I'd step in and do more. And let her have a break. But it's, yeah, a lot of it was communication.</i></p>

			<p><i>It's so important. I mean it's one thing I know from any relationship is that you've got to communicate, cause if you go and bottle something up it just gets worse and worse, to the point where it becomes a problem. So we've always said from the beginning, we just talk about everything.</i></p> <p><i>when I sort of watched her with the adults at this centre, she was... very mature with them, very well organised, very caring and she seems to be able to sort of change herself... I don't know the words to explain it. The way she acts to be, you know within a different environment, if you see what I mean.</i></p> <p><i>quite often my relationships make me notice these things,</i></p>
		Closeness	<p><i>And we just generally... we talk about everything. I mean there's nothing we don't talk about.</i></p> <p><i>Well, I think it's difficult for my husband because he's not been involved. And... I think he's got blinkers on so I don't think he'd ever see anything positive in it at all.</i></p>
	Valuing		<p><i>I actually feel really quite chuffed because I didn't realise how much I actually did. I think cause obviously when you think, what do you do? You think, oh nothing really. Just do what I do. But when you change it and say... [descriptions of impact of particular acts] I feel really happy with myself that I can finally give something back, because after all that time of them helping me, I'm now... I know for a fact that I'm helping them back.</i></p> <p><i>it probably wouldn't make a difference but I get... because I worry that it does make a difference that's probably why I put too much pressure on myself, that's probably why I got ill in the first place.</i></p>

			<p><i>Because I didn't used to be like this, I was very... I think I was very different back in the day but then obviously back in the day was when I was young, so... I think a lot of things have contributed to that but mostly it would be... self-faith... that comes from support from the people around me I suppose,</i></p> <p><i>it's the fact that it gives her value because she is doing things, so in being valued by other people, she then values herself... she's got a lot of ability but she couldn't actually use it. Or have it recognised because it's also quite important to have people recognise that you've got the ability.</i></p>
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Appendix X Early diagrammatic models

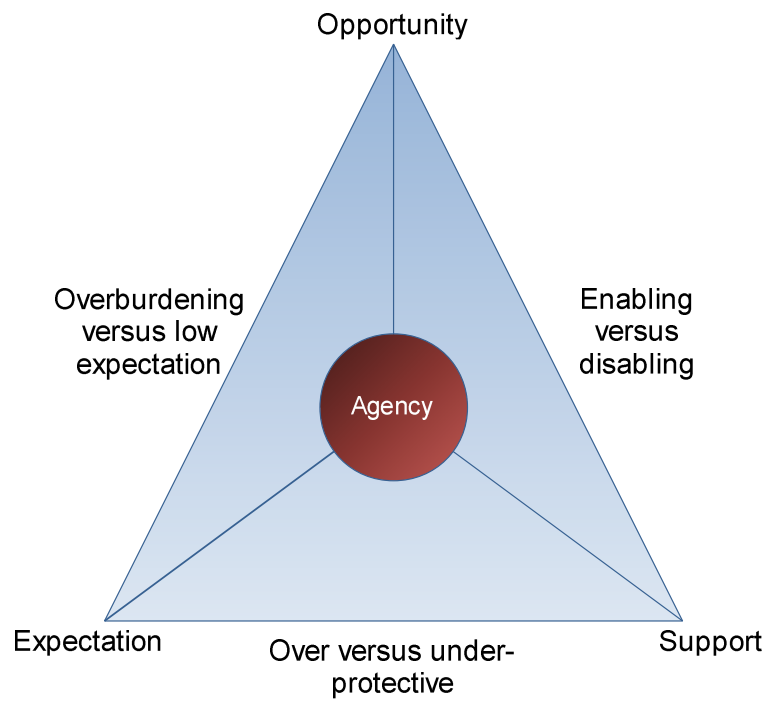


Diagram highlighting the relationship between expectation, support, opportunity and agency

Appendix XI Guidelines for Journal of Mental Health

Instructions for Authors

Journal of Mental Health is an international journal adhering to the highest standards of anonymous, double-blind peer-review. The journal welcomes original contributions with relevance to mental health research from all parts of the world. Papers are accepted on the understanding that their contents have not previously been published or submitted elsewhere for publication in print or electronic form.

Submissions

All submissions, including book reviews, should be made online at Journal of Mental Health's Manuscript Central site at <http://mc.manuscriptcentral.com/cjmh>. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. Please note that submissions missing reviewer suggestions are likely to be un-submitted and authors asked to add this information before resubmitting. Authors will be asked to add this information in section 4 of the on-line submission process. The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do include the abstract, tables and references in this word count.

Manuscripts will be dealt with by the Executive Editor, Professor Til Wykes, Department of Psychology, Institute of Psychiatry, De Crespigny Park, London, SE5 8AF, United Kingdom. It is essential that authors pay attention to the guidelines to avoid unnecessary delays in the evaluation process. The names of authors should not be displayed on figures, tables or footnotes to facilitate blind reviewing.

Book Reviews. All books for reviewing should be sent directly to Martin Guha, Book Reviews Editor, Information Services & Systems, Institute of Psychiatry, KCL, De Crespigny Park, PO Box 18, London, SE5 8AF.

Manuscripts should be typed double-spaced (including references), with margins of at least 2.5cm (1 inch). The cover page (uploaded separately from the main manuscript) should show the full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names, the exact word length of the paper and affiliations of authors and the address where the work was carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

Abstracts. The first page of the main manuscript should also show the title, together with a structured abstract of no more than 200 words, using the following headings: Background, aims, Method, Results, Conclusions, Declaration of interest. The declaration of interest should acknowledge all financial support and any financial relationship that may pose a conflict of interest. Acknowledgement of individuals should be confined to those who contributed to the article's intellectual or technical content.

Keywords

Authors will be asked to submit key words with their article, one taken from the picklist provided to specify subject of study, and at least one other of their own choice. Text. Follow this order when typing manuscripts: Title, Authors, Affiliations, Abstract, Key Words, Main

text, Appendix, References, Figures, Tables. Footnotes should be avoided where possible. The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do include the abstract, tables and references in this word count. Language should be in the style of the APA (see Publication Manual of the American Psychological Association, Fifth Edition, 2001).

Style and References. Manuscripts should be carefully prepared using the aforementioned Publication Manual of the American Psychological Association, and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes et al., 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a). The reference list should begin on a separate page, in alphabetical order by author (showing the names of all authors), in the following standard forms, capitalisation and punctuation: a) For journal articles (titles of journals should not be abbreviated): Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. *Magnetic Resonance Imaging*, 18, 351–355. b) For books: Powell, T.J. & Enright, S.J. (1990) *Anxiety and Stress management*. London: Routledge c) For chapters within multi-authored books: Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In G. Parry & F. Watts (Eds.), *A Handbook of Skills and Methods in Mental Health Research* (pp. 75–89). London: Lawrence Erlbaum. Illustrations should not be inserted in the text. All photographs, graphs and diagrams should be referred to as 'Figures' and should be numbered consecutively in the text in Arabic numerals (e.g. Figure 3). The appropriate position of each illustration should be indicated in the text. A list of captions for the figures should be submitted on a separate page, or caption should be entered where prompted on submission, and should make interpretation possible without reference to the text. Captions should include keys to symbols. It would help ensure greater accuracy in the reproduction of figures if the values used to generate them were supplied. Tables should be typed on separate pages and their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but not in the body of the table. Words and numerals should be repeated on successive lines; 'ditto' or 'do' should not be used.

Accepted papers

If the article is accepted, authors are requested to submit their final and revised version of their manuscript on disk. The disk should contain the paper saved in Microsoft Word, rich text format (RTF), or as a text or ASCII (plain) text file. The disk should be clearly labelled with the names of the author(s), title, filenames and software used. Figures should be included on the disk, in Microsoft Excel. A good quality hard copy is also required.

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Appendix XII End of study Letter NHS Ethics panel

Dr Ray Godfrey
Care of Sharon Busbridge
National Research Ethic Service
Kent Research Ethics Committee
South East Coast Strategy Health Authority
Preston Hall
Aylesford Kent
ME20 7NJ

Dear Dr Godfrey,

Study Title: **What beliefs are held by individuals who have experienced first-episode psychosis and their families about their capacity to make a positive contribution to their families?**
REC reference: **10/H1101/87**

I am writing to inform you that this study has now been completed and the dissertation is in the process of being submitted. I am including a brief summary of the findings below. Please do not hesitate to contact me if you would like any further information.

Kind regards

Dr. Justin Allman
Trainee clinical psychologist
Department of Applied Psychology
Canterbury Christ Church University
Salomons Campus
Broomhill Road
Tunbridge Wells, Kent TN3 0TG

Aim. The aim of this grounded theory study was to explore whether individuals who have experienced first-episode psychosis positively contribute to their families.

Method. Fifteen participants took part in the study, seven had direct experience of psychosis, seven were relatives and one was a partner of an individual with direct experience. Participants were interviewed separately, with the accounts analysed using Charmaz's version of grounded theory (Charmaz, 2006).

Results. The constructed theory suggested that individuals who have experienced first episode psychosis can and do contribute to their families, and that such contribution when noticed and valued can lead to an increase in well-being. The model suggests that contribution is shaped by the self-concept, the impact of psychosis, the opportunity for contribution and whether it is noticed.

Conclusion. The constructed theory extends current research, and suggests that contribution can positively impact both the individual and family. Limitations and clinical implications of the research are explored and suggestions for further research given.

Appendix XIII Ethics and R&D letters

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