MAJOR RESEARCH PROJECT

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UNDERSTANDING WOMEN’S EXPERIENCES OF PSYCHOTIC PHENOMENA

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CANTERBURY CHRIST CHURCH UNIVERSITY
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Summary of the MRP portfolio

Section A provides a review of the literature pertinent to women with longstanding mental health difficulties. It examines the particular risks women face due to their nature of their lives and critically considers some of the obstacles to gender based research in the area. Attention is drawn to the experience of psychotic phenomena and theoretical considerations which show the contribution of psychosocial influences to their development are discussed. This is followed by an exploration of the empirical evidence of the relationship between the content of adult psychotic symptoms and childhood traumatic experience. The results point to the psychosocial nature of such symptoms. Implications and areas of future research are discussed.

Section B presents the findings of a qualitative study which aimed to explore women’s understandings of their delusions in the context of their lives. The paper gives a background and rational for the study, describes the procedure whereby participants were recruited to the study and justifies the use of grounded theory methodology. Findings are presented and discussed with clinical and research implications.

Section C provides a critical appraisal of the research methodology and findings, and elaborates on clinical implications and future research ideas discussed in Section B.

Section D contains appendices of supporting material.
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Section A: Review of the Literature

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UNDERSTANDING WOMEN’S EXPERIENCES OF PSYCHOTIC PHENOMENA

Section A: Women and psychotic symptoms. A literature review

Word Count: 5371

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Abstract

Recent documents such as the Department of Health’s (2003) guidance on Mainstreaming gender and women's mental health recognise the particular needs of women with mental health problems and the importance of meeting them. The key message is that services need to be sensitive to gender differences in mental health problems with importance placed on the latent causes and context of women’s problems in addition to their symptoms. This review focuses on the evidence about women with psychotic symptoms present in several psychiatric disorders classified as Serious Mental Illness. It is divided into three parts. First, there is a consideration of the obstacles to gender-based research in the group of individuals with longstanding mental health problems and the particular risks this subgroup of women face due to the context of their lives. Second, there is an introduction to the field of psychotic phenomena followed by a brief review of studies which have used gender as a paradigm to understand such symptoms. Third, there is an exploration of the empirical evidence of the relationship between the content of adult psychotic symptoms and childhood abuse. The findings consistently indicate an association between symptom content and childhood trauma. Clinical and theoretical implications are considered and areas of further research identified.
Introduction

Documents such as the recent publication of the World Health Association (WHO; 2012) and the International Women’s Mental Health Consensus Statement (Stewart, 2006) recognise gender as a key determinant of mental health inasmuch as it influences the power and control men and women have over factors that increase the susceptibility and exposure to mental health risks. Social and interpersonal factors such as poverty, victimization and sexual abuse are “alarmingly high” in women while their status and life opportunities remain “tragically low” worldwide (WHO, 2012, p. 19). Gender inequalities in paid employment, women’s “double day” of work inside and outside home, the increased chances of being a single parent as well as the specificity of women’s life cycle in terms of reproductive function and health are part of their realities (Stoppard, 2000, p.13; Ussher, 1991; 2000). This means that women with mental health problems face particular risks and vulnerabilities due to the nature of their lives. The Department of Health’s (2003) guidance on Mainstreaming Gender and Women’s Mental Health implies that services have hitherto neglected gender differences not only in terms of the nature and prevalence of psychopathology, but also in terms of their lives, the context in which they are embedded, and their stresses and responsibilities that contribute to mental health problems. It appeals for gender sensitive care that acknowledges the specific needs of women.

Aims

This review focuses on women who experience psychotic symptoms such as hallucinations and delusions, which are considered signs of Serious Mental Illness (SMI). The term SMI is used widely in psychological research (British Psychological Society; BPS, 2000) and is thought to be less laden with negative meaning. It implies that the person is not
the same as the illness, but it continues to punctuate the seriousness and overall impact (Harlene & Bernhard, 1994). The questions of the current review are:

1. Are there gender differences in psychotic symptoms?

2. Is the content of psychotic symptoms associated with childhood trauma?

3. Therefore, is the policy guidance justified for women experiencing psychotic symptoms?

**Women and SMI**

Gender-based research into SMI has been slow to gain momentum (Kulkarni, 1997) with women being poorly represented in the literature (Repper, Perkins & Owen, 1998). In the case of people with SMI, men suffering from schizophrenia are the most dominant group overshadowing women and increasing their invisibility (WHO, 2012). This is also reflected in studies of populations with longstanding difficulties and the predominantly male samples used (Thompson et al., 2010). The lack of interest in gender based research is partly related to the non-significant gender differences in terms of SMI prevalence (WHO, 2012). However, several epidemiological studies have reported gender differences in onset, course and outcome, which warrant the study of women with SMI as a separate phenomenon (Al-Issa, 1982; Gearon & Rachbeisel, 2002; Grossman, Harrow, Rosen, Faull & Strauss, 2008; Piccinelli & Homen, 1997). A gender-based approach may also contribute to the reduction of the ambiguity inherent in the study of SMI given that it incorporates syndromes such as schizophrenia infamous for their heterogeneity and the empirical and theoretical impasses this incurs (Ochoa, Usall, Cobo, Labad & Kulkarni, 2012).

**Developmental and environmental contexts of women with SMI**

Social factors, which are linked with an increased risk of mental illness, such as isolation and poverty are more common in women with SMI, as is the experience of child sexual abuse, sexual and domestic violence (Williams, 2005; World Health Organisation,
2012). Not all women who suffer childhood abuse develop mental health problems, however many studies indicate a strong association with mental disorders and psychological problems such as depression, anxiety, PTSD, somatisation, eating disorders and relational problems such as difficulty in trusting others, feelings of guilt, shame the need for secrecy and extremely low self-esteem (Ellenson, 1985; Stoppard, 2000). There is consistent evidence that the prevalence of violent victimization of women with SMI is unusually high (Bengtsson-Tops & Ehlisasson, 2012; Goodman, Rosenberg, Mueser & Drake, 1997). In a review of the research on this topic, Goodman et al. (1997) found that across the 13 studies judged to be most methodically executed, 51 to 97% of women reported to have been physically or sexually abused at some point in their lifetime, suggesting that most of the women with SMI have possibly been victimized in this way. At the same time, the mortality rate for that group of women is increasing, reaching the standardized mortality rate for men both for unnatural and natural causes of death (Høye, Jacobsen & Hansen, 2011). This rate is highest in the group of women diagnosed with schizophrenia with a history of admissions suggesting that there is a subgroup of vulnerable women in the community whose needs are easily overlooked, but who warrant particular attention (Høye et al., 2011; Stewart, Ashraf, & Munce, 2006).

A symptom-based approach to understanding SMI

Doubts about the reliability and validity of the concepts of schizophrenia and psychosis described as a “semantic Titanic, doomed before it sails”, concepts that are so heterogeneous and “so diffuse as to be unusable in a scientific context” (Bannister, 1968, p. 181) have led researchers to adopt a symptom-based approach by focusing on specific experiences (e.g. Bentall, 2004a; 2004b; Hagen & Turkington, 2011). Thus, traditionally linked with the positive symptoms of schizophrenia, hallucinations (the experience of hearing voices) and delusions (having unusual beliefs) are now studied independently. This research trajectory
has been corroborated by studies which indicate that these symptoms do not fit well into neat
categories such as diagnoses (Serretti et al., 2001), they are on a continuum with normality
(Johns & van Os, 2001) and are common in several disorders classified as SMI (Johns, Peters
& Kuipers, 2007). In this review the term psychotic symptoms refers to hallucinations and
delusions (HD).

**Gender differences in psychotic symptoms**

In order to delineate the terrain of gender differences in psychotic symptoms a
literature search was conducted focussing on those studies which used gender as a paradigm
for understanding symptomatology. Those that did not analyse results by gender were not
included (For search terms see Appendix A). In a literature review of gender differences in
schizophrenia, Chue (2000) found that certain positive symptoms (e.g. auditory
hallucinations and persecutory delusions), were significantly greater in women than men.
Other studies have reported higher prevalence of persecutory delusions in women than men
(Castle, Sham, Bessely, & Murray, 1994; Goldstein & Link, 1988; Gutierrez-Lobos, Schmid-
Siegel, Bankier & Walter, 2001) while Galdos and van Os (1994) reported significantly more
frequent sexual delusions in a sample of young women who had been admitted for the first
in a subsample of 155 (93 women, 62 men) admitted individuals meeting criteria for a manic
episode and displaying psychotic symptoms. Women had significantly more hallucinations
and delusions, both overall and per patient, compared to men. They also had significantly
more delusions of reference and paranoid delusions than men. The authors concluded that
women with bipolar mania displayed a more severe acute episode and course of illness than
men with the same diagnosis and that gender differences in bipolar have not been adequately
addressed.
Nevertheless, others failed to report such differences: Chang et al. (2011) reported no differences in psychotic symptoms in a first episode psychosis study, a trend which was corroborated by a recent review of the literature in first episode psychosis (Ochoa et al., 2012). In a 20-year longitudinal study of psychosis and recovery women were reported to have lower rates of psychotic activity over the course of illness compared to men (Grossman et al., 2008).

Overall, findings on gender differences in psychotic symptoms are inconclusive. Some of the inconsistencies in the literature may be explained by methodological issues. For example, reporting the overall symptom score without looking at symptom specific items, sampling bias introduced with over-representation of men, the use of inpatient samples including more severely ill women, different doses of antipsychotic medication with different effects on symptomatology and the inclusion of samples at different stages of the illness. A common limitation of the studies reviewed here inasmuch as they take gender as a paradigm for understanding psychotic symptoms is the reliance on biomedical explanatory models such as the “oestrogen hypothesis” emphasising the protecting effect of oestrogens known to have a neuroleptic-like effect, and gender differences in neurodevelopmental profile. At the same time they consistently overlook the influence of the psychosocial context in the manifestation of gender differences.

**Theoretical considerations**

The symptom-based paradigm has led to the conceptualization of a cognitive model of positive symptoms of psychosis which incorporates social and cognitive factors that shape and maintain HD (Garety, Kuipers, Fowler, Freeman & Bebbington, 2001). At its core is the idea of a biopsychosocial vulnerability triggered by an event. The appraisal of the experience is what leads to the psychotic symptoms. The appraisal has been found to be influenced by a)
dysfunctional schemas about self and the world, b) reasoning and attributional biases and c) isolation and adverse environments. The ‘jumping to conclusions’ reasoning bias has been found to be of particular relevance to delusions with individuals collecting less evidence before reaching a decision (Garety et al, 2001), while the role of low self-esteem in the development of persecutory delusions is also well established emphasizing the defensive function of the symptom (Bentall, Kinderman & Moutoussis, 2008). Bentall, Kinderman and Kaney (1994) have also highlighted the attributional errors made in people with psychosis with the tendency to attribute negative events to others. Expressed emotion in the family environment has been found to be an established predictor of relapse in psychosis (Bebbington & Kuipers, 1994) while more recently there has been renewed interest in the role of childhood trauma and adversity occurring years before the onset of psychosis (Kuipers, Garety, Fowler, Freeman, Dunn & Bebbington, 2006). Thus childhood victimization creates negative self and other schemas, whereby the victim feels weak and powerless, frightened and with no control over their lives. The past traumatic experience affects both information and emotional processing leading to intrusions, which are then misconstrued and appraised as psychotic symptoms (Kuipers et al., 2006). Given that violence is highly gender specific (Mezey & Stanko, 1996) and disproportionately more women than men with SMI report adult victimization there is a high risk of women being caught in “pernicious, continuous cycles of experiences of trauma, mental illness and retraumatization” (Peters, 2000, p. 444).

Even though it has been extended to account for early trauma, essentially the cognitive model takes a biopsychosocial approach known as the stress vulnerability paradigm of understanding mental distress (Zubin & Spring, 1977). It implies that a stressful life event can trigger the underlying vulnerability to an illness such as psychosis. However, this paradigm has subsequently been criticized owing to its lack of explanatory power inasmuch
as all human behaviour can be accounted for in this way as well as its emphasis on the underlying disease triggered by the life event (Johnstone, 2012). Thus what is examined is not the impact of the life event but this unknown underlying biological vulnerability that finally got expressed.

The psychodynamic model of understanding psychosis originates in Freudian psychoanalysis and stresses drive-related conflicts in psychosis that result in defenses. The ego rejects the incompatible idea together with its affect and behaves as if the idea had never occurred to the ego at all (Freud, 1894). The unpalatable thought is so radically split off from consciousness that it returns from the outside sometimes in the form of a hallucination (Leader, 2012). In their attempt to symbolize and make sense of the bizarre phenomena of psychosis, the subject will respond by forming a delusional interpretation thereof, which-similar to the cognitive model-is essentially a form of faulty reasoning. Thus the psychodynamic tradition conceptualizes the delusional formation as “an attempt at recovery, a process of reconstruction” whereby the new reality does not raise the same objections as the old one (Freud, 1911, p.71; 1924). Freud adds that this transformation of reality is carried out upon “memory-traces, ideas and judgments which have been previously derived from reality and by which reality was presented in the mind” (1924, p.185). Thus Freud laid the foundations for a psycho-socio-biological understanding of psychotic symptoms within the context of a person’s life, circumstances and culture, and their attempts to find meaning in their experiences (e.g., Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002).

**Trauma and psychotic symptoms**

Among the Recent Advances in Understanding Mental Illness and Psychotic Experiences identified by the BPS (2000) is the finding that “many people who have psychotic experiences have experienced abuse or trauma at some point in their lives” (p.28).
The interest in the role of the environment and in particular childhood trauma in the development of psychotic disorders has recently been rekindled (Johnstone, 2007, Read, van Os, Morrison & Ross, 2005). People abused as children are 9.3 times more likely to develop psychosis while the risk rises to 48 times for the severest abuse (Janssen et al. 2004) and the link appears to be a causal one with a dose-dependent relationship between severity and frequency of abuse and psychotic symptoms (Bebbington et al., 2011; Read et al., 2005). Mueser et al. (1998) estimated that of 153 severely ill women, 52% were sexually abused as children and nearly 64% experienced sexual abuse later in life suggesting that the majority of psychotic women have been subject to victimization on more than one occasion.

**Rationale of review**

Nevertheless, despite these alarming figures, the increasing acknowledgement of the role of trauma in the manifestation of psychotic disorders, and the conceptualization of symptoms as meaningful, there is little interest in the actual content of psychotic symptoms. Harper (2008) attributes this to the biological and reductionist traditions in psychiatry, which tend to downplay the function and meaning of the symptom. Yet an exploration of the nature of the association between psychosocial experience and the phenomenology of the symptoms in SMI could provide further insight into the potential psychosocial nature of psychotic phenomena and their meaningfulness. Recent research on trauma and psychosis has provided some evidence linking particular kinds of abuse with particular symptoms, for example, childhood sexual abuse with auditory hallucinations and chronic victimization such as bullying with paranoid delusions (Read, Bentall & Fosse, 2009; Read & Bentall, 2012), but what is unclear is whether the actual content of hallucinations and delusions is linked to the trauma. Owing to the absence of relevant literature in areas other than trauma and particularly childhood trauma, this review will focus on the five identified studies, which investigated the
direct relationship between psychotic symptom content and childhood trauma; they are reviewed below.

**Methodology**

Online literature databases and trial registers were searched for empirical articles exploring symptom content and childhood trauma published in English-language peer-reviewed journals (see Appendix A for search strategy). Results were manually inspected and supplemented by tracking relevant citations. Reports excluded from the review were those with male only samples, mixed sample studies that did not analyse data by gender or by symptom (i.e. HD) studies on puerperal psychosis, and those that referred to type of symptoms without elaborating on the content. For this review trauma is defined as sexual or physical abuse incurred in childhood (CA). Five studies were identified and are reviewed below in chronological order.

**Review of empirical literature**

**Ellenson (1985)**

Ellenson carried out in-depth Mental Status Examination (MSE) interviews to examine the symptomatology in 40 adult female incest survivors. He identified a pattern of disturbances unique to this group of women, consisting of thought content and perceptual disturbances. The latter included recurrent hallucinations across modalities, which the author considered “flashbacks” (p. 530), inasmuch as they “amount to a disguised recall of painful childhood experiences” (Ellenson, 1985, p.532). Thus, visual hallucinations contained “shadowy figures” described as “dark, featureless silhouettes”, experienced as male and as evil or dangerous seen only when at home (Ellenson, 1986, p. 152). Voices invariably consisted of intruder sounds, were persecutory or directive instructing the adult survivor to harm or kill herself or commit an act of violence (Ellenson, 1986). Hallucinations in other modalities were also described and found to be associated with the trauma history.
Ellenson underlined the difficulties encountered when researching this area such as the tactics that survivors develop over the years to minimize the impact of symptoms as well as their disinclination to reveal their symptoms lest they are thought to be mad. By using MSEs as an investigative technique, he was able to achieve a thorough examination of the details of the symptom, which could have otherwise been missed.

**Beck & van der Kolk (1987)**

Through record review and staff interviews, Beck and van der Kolk examined the clinical characteristics of a cohort of 26 female patients (median age = 36.5 years) in a state hospital unit in Boston who remained actively psychotic despite psychopharmacological and psychosocial treatments. History of incest was gathered from participants’ statements and was found in 12 (46%) of the 26 cases. The 12 women differed significantly from the rest of the sample without such a history on a number of factors including the prevalence of sexual delusions (five vs. none, p = .009). Of the five women, one believed that her “body was covered with ejaculate” and another that she had had intercourse with public figures (1987, p. 1475). Two were compulsively sexually active while a sixth patient was preoccupied with thoughts of sexual nature and was also compulsively sexually active. Nevertheless, methodological limitations (reliance on self-reports found in notes, small sample size and the lack of a control group) necessitate the evaluation of the correlation by more rigorously designed studies.

**Read & Argyle (1999)**

Read and Argyle examined the records of 100 consecutive admissions to a psychiatric inpatient unit in New Zealand. This was part of a study looking into the value of taking history of abuse upon admission to an acute care hospital. The records of 22 individuals with reported history of CA were further scrutinized and the presence and HD content were
recorded. Twelve of the 22 individuals were women (mean age = 35.6 years, SD = 8.6), 17 of which (77%) exhibited positive symptoms of psychosis.

Eleven instances of reported hallucinations and ten instances of delusions were found in the records of the 22 abused patients though the actual content of the symptoms was described in only 13 instances. In the remaining instances, symptoms were described merely by type (e.g. auditory hallucinations, paranoid delusions). Altogether, in seven (54%) of the 13 instances in which symptom content was described, it appeared related to the traumatic experience of abuse. Read and Argyle gave an example of a woman whose file indicated she was an incest survivor, abused from the age of five. She was hearing command hallucinations telling her to kill herself as well as “male voices outside her head and screaming children’s voices inside her head” (p. 1469). In the case of delusions, persecutory ideation was the most frequent category while an example of the content related to CA was a woman whose delusion entailed the belief that “men were out to get her and harm her and sexually harass her” (p 1470).

Similar to the previous study, Read and Argyle (1999) used a chronic psychotic population and relied on clinical records to confirm CA. Rather than doubt the veracity of reported statements they pointed out the risk of underestimating the prevalence of abuse when relying on case notes. The overall small sample, the absence of recorded symptom content in many of the cases and of a control group to compare symptom content in abused and non-abused individuals did not allow for robustness in the findings. In addition, although half of the sample consisted of women, gender issues were not considered. However, the preliminary findings of this exploratory study indicated that the HD content was related to the CA in about half of the patients. Read and Argyle marked a shift in attention from a biological towards an environmental understanding of the experiences of people with
psychotic symptoms which has hitherto been more robustly supplemented (Read & Colin, 2003; Read et al., 2005).

**Thompson et al. (2010)**

Thompson et al. observed the high incidence of psychotic symptoms with sexual content as well as the growing research on trauma, particularly sexual trauma and its role in the onset of psychosis. They sought to explore whether a history of sexual trauma impacts on the content of psychotic symptoms and more precisely, whether it results in higher rates of symptoms with sexual content than those manifested in individuals without such a history. They used an “ultra high risk” (UHR) population, defined by the presence of attenuated psychotic symptoms usually present in the “prodromal” period preceding the onset of frank psychotic symptoms (Thomson et al., 2010, p. 85). The sample consisted of consecutive patients who were treated in a mental health service in Melbourne, treating young people in the UHR population between April and October 2007. Participants completed the Comprehensive Assessment of At-Risk Mental States (CAARMS; Yung et al., 2005), a popular instrument with excellent psychometric properties, designed to ascertain the presence of attenuated psychotic symptoms. Patients’ history of trauma was rated by clinicians using a trauma questionnaire designed by the authors, reflecting the list of events regarded as traumas according to DSM IV. Information about the content of psychotic symptoms was also collected by the clinicians who worked with the patients.

The sample consisted of 92 patients (mean age = 18 years, SD = 2.95), predominantly female (65%). Fourteen patients (15.2%) reported psychotic symptoms whose content was overtly sexual. Of the 33 patients (35.9%) who reported sexual trauma, 11 (33.3%) had at least one attenuated positive symptom of psychosis with sexual content and 15 (45.5%) experienced at least one symptom of delusions/overvalued ideas of the persecutory type.
Patients with a history of sexual trauma had significantly more attenuated psychotic symptoms of sexual content than those without such a history ($t = -3.72, P < 0.001$). Thus the results suggested a strong association between the experience of sub-threshold psychotic symptoms of sexual content and history of sexual trauma, which remained significant after controlling for the experience of other categories of trauma (physical) and differential diagnosis (PTSD).

Women had higher rates of CA than men with significant differences ($P < 0.001$) in the case of sexual abuse (50% vs. 9.4%) and in particular, the trauma of rape (36.7% vs. 0.0%) and sexual molestation (38.3% vs. 9.4%). Women who had been subject to these two types of trauma were also significantly younger than those who had not reported such abuse.

Thompson et al. (2010) noted a gender difference in terms of symptom content: women had significantly higher rates of symptoms with sexual content than men (13.3% vs. 0.0%) and in particular, significantly higher rates of delusions of being watched of a sexual nature and of undressing ($P < 0.05$). Directly related sexual psychotic symptoms and intrusive thoughts of sexual nature were also significantly more prevalent in women than men ($P < 0.05$).

Despite this striking gender difference both in terms of prevalence of sexual trauma and sexual content, Thompson et al. did not explore the interaction between women who had been sexually abused and the content of their symptoms. In addition, for both symptom content and assessment of trauma, they relied on interviews with case managers instead of interviewing patients themselves. Compared to previous studies the original sample size was large, however the number of patients with symptoms of sexual content was low and bigger samples would be beneficial for more conclusive findings.
Reiff, Castille, Muenzenmaier & Link (2012)

Reiff et al. carried out a study exploring the interaction between CA and adult symptom content. Participants were recruited from outpatient clinics in two New York City boroughs. Their sample emerged from a larger study evaluating treatment outcomes for people with SMI. A subsample of individuals reporting both sexual and physical abuse was selected alongside those who reported neither in order to maximise contrast between the groups. Out of the 87 eligible respondents, 30 individuals (22 with both types of CA) for whom information about HD content was available were invited to participate. In the final sample, the average age was 37.3 years and mostly males (56.7%). Information was collected via interviews, which included administration of the Histories of Physical and Sexual Abuse Questionnaire (HPSAQ; Meyer, Muenzenmaier, Cancienne & Struening, 1996), a standardized tool with good psychometric properties, a semi structured diagnostic interview (SCID; First & Gibbon, 2004) and specific questions to elicit the content of psychotic symptoms.

The narrative sections of the interviews were subject to qualitative analysis first, to compare symptom content between CA and non-CA groups and secondly, to compare descriptions of CA and HD content in individuals cases. For the group comparison Reiff et al. combined thematic content analysis and grounded theory techniques in order to identify “Trauma-Relevant Symptom Content” (p.358): they developed a coding scheme based on CA literature and findings on the relatedness of symptom content. For example, from Read and Argyle’s (1999) study they elicited codes such as “sexual delusions”, “auditory hallucinations in the voice of the abuser, “voices making derogatory comments with a sexual theme” (Reiff, et al., 2012, p. 358). These codes were supplemented by identifying additional ones emerging from the data. Eventually nine categories of symptom content were subsumed in a “Trauma-
 Relevant Symptom Content” score. The comparison showed the CA group had a significantly higher score than the non-CA group.

The examination of individual case studies for the assessment of congruence between symptom content and CA was done by drawing on the Core Conflictual Relationship Theme Method (Luborsky & Cris-Christoph, 1998), a tool of narrative analysis developed to evaluate patterns of relating. It was modified in order to evaluate the correspondence between CA and symptom content. Of the 21 cases (10 females, 10 males) that were coded, two thirds (n=14) showed some relatedness while there were direct associations in two cases.

Experiencing the others as “threatening” or “forceful” and the experience of being hurt or threatened were the most popular codes among those whose data were analyzed. Reiff et al. also coded the symptom content of participants with no history of abuse and found that half of the respondents perceived the other’s response as positive, one as neutral, one as provocative and two suggesting that the individual would be killed or that they should hurt themselves. This analysis showed that the respondents’ descriptions of CA were related to the themes present in adult psychotic symptoms. Nondisclosure at the time of the abuse was a frequent theme encountered among those with a history of abuse while three participants expressed reluctance to disclose adult symptom content for fear they would not be believed by the doctors or that there would be negative repercussions such as increase in medication and hospitalization. No problems regarding disclosure were observed in the non-CA individuals.

This was a sophisticated and well executed study utilizing two analytic strategies in order to elucidate the relationship between CA and adult psychotic symptoms. It highlighted the need to elicit detailed symptom content owing to its possible link with past trauma, which is often underreported. Its clinical recommendations should be considered alongside the limitations of this study, which included the small sample size as well as not accounting for
the effects of gender. Similar to previous studies, Reiff et al. reported the risk of bias when relying on retrospective self-reports. However, they limited this by checking the file notes.

Discussion

The studies reviewed support theory suggesting the importance of the environmental contribution to the expression of psychotic phenomena by finding an association between HD content and childhood trauma (Read et al., 2005; Read & Bentall, 2012). Evidence across the studies suggests the relatedness of psychotic symptom content to abuse, which may support the conceptualization of symptoms as psychosocial phenomena, meaningful within the context of a person’s life experiences (Freud, 1924; Bentall, 2004a). Nevertheless, such findings should be interpreted tentatively, given the aforementioned methodological limitations which are further considered below as well as the limited number of the studies reviewed.

Implications for services

The implications of a possible association between childhood trauma and HD content are serious. Professionals need to draw attention to what is being said and be aware of the possibility that these symptoms may be actual or symbolic representations of early experiences (Read & Bentall, 2012). Despite the recent NHS confederation guidelines (2008) “there is a notable reluctance on the part of mental health professionals of all disciplines to routinely explore service users’ experiences of abuse” (p.2). Patients need to be asked about such experiences, particularly child abuse while there should be awareness of the tendency of survivors to withhold such information. The high rates of abuse history among women with SMI make it imperative that gender is clinically addressed by integrating it into women’s care plans. The policy guidance is right to insist that gender issues are also clinical issues requiring gender-sensitive services whereby the needs of women are addressed (Bartlett,
2003, DoH, 2003); by not initiating exploration of abuse, staff may contribute to the confirmation of a woman’s belief in the need to deny the truth of their experience and inadvertently engage in a pernicious cycle of retraumatisation. At the same time, curiosity should be maintained in the face of symptom manifestation such as HD. The focus should not be on the alleviation of symptoms inasmuch as these are not the real problem; the manifested distress via the symptom may be the result of a deeper injustice that has occurred in the past and is susceptible to recurrence unless awareness of the psychosocial nature of HD is raised and responded to adequately.

**Implications for Clinical Psychology**

In a service culture whereby the priority is on changing symptoms and behaviours rather than looking at the causes (NHS confederation, 2008), the meaningfulness of HD has important implications. It suggests that the distressing confusion of people who experience psychotic phenomena might be better understood by taking a psychosocial approach whereby the symptom is something to be understood in the context of a person’s life experiences. Psychologists have an important role to play in putting together meaningful formulations and accessing a unique understanding in work with their clients. Their contribution is vital in helping staff to make sense of such symptoms and in raising awareness to environmental factors that might be exacerbating the manifest problems.

**Limitations and implications for further research**

The reviewed studies have methodological limitations, which are difficult to address in this type of research: reliance on self-reports introduces potential error however, research in SMI suggests that this would take the form of underreporting (Goff et al., 1991; Read & Collin, 2003). The small sample sizes and the absence of content descriptions restricting the data available for analysis undermine the robustness of the studies. More importantly, except
for the two studies which used female-only samples and confirmed the strong links between symptom content and CA, two did not consider gender and one failed to do so despite strong evidence suggesting a gender difference. Lastly, almost all the studies reviewed, explored literal links with explicit content whereas content may be more metaphorical or indicative of more generalized impact of abuse as shown by Reiff et al (2012) with popular codes centring on feeling threatened and hurt.

In the face of consistent evidence that a history of sexual or physical abuse is unusually common in women with SMI and the accumulation of evidence of the association of childhood trauma with psychosis, future research should focus on the contextual contingencies that impact on women suffering from psychotic disorders. Areas that merit investigation are women’s delusional beliefs and their relationship to life events, and the contextual factors that might be contributing to the expression of psychotic symptoms. Another potential area of research could be to examine interventions for change in sociopolitical structures that maintain social inequality. In that way, the focus may shift from locating the problem within the individual to targeting ubiquitous problematic structures.
References


psychosis population: Frequency and association with sexual trauma. Psychiatry Research, 177, 84-91.


Section B: Empirical Paper

MAJOR RESEARCH PROJECT

PEGGY PAPADA BA (Hons), MA

UNDERSTANDING WOMEN’S EXPERIENCES OF PSYCHOTIC PHENOMENA

Section B: Women’s understandings of their delusions in the context of mental health services and their lives: A grounded theory analysis.

Word Count: 7990

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY
Abstract

Objectives. Psychotic phenomena such as delusions have recently been understood as meaningful within the context of a person’s life while recent models of psychosis implicate psychosocial influences in its aetiology. Research on women with such experiences has been limited despite recognition of their specific needs and vulnerabilities due to the nature of their lives. This study aimed to examine the processes influencing women’s understandings of their delusional beliefs in the context of their lives.

Design. This study used a social constructionist version of grounded theory to conceptualize the process of women’s understandings.

Methods. Ten women who had experienced delusions were interviewed.

Results. Grounded theory analysis revealed four main processes: Women’s acquisition of knowledge about themselves, significant life experiences, how women experience their delusions, and the process of emerging from the delusional world.

Conclusions. According to the constructed theory, the core process of understanding is conceptualized as residing in the space between private experience and the social world. It is mediated by the relationship women have to knowledge about the self, which in turn is mediated by the responses of others. Delusions are understood as responses to life experiences and are therefore meaningful containers of truth. Implications for clinical practice, limitations and suggestions for further research are discussed.

Practitioner Points

- Encourage women to explore their experiences further so that they can create narratives and substantiate their sense of self.
- Women silence and isolate themselves as a way of coping. Allow space for verbalization through the gradual establishment of the therapeutic relationship.
Women’s Understandings of their Delusions in the Context of Mental Health Services and their Lives

Traditionally associated with schizophrenia as one of its defining characteristics, delusions are one of the most important constructs used by psychiatrists to diagnose patients who are considered to have lost touch with reality (Maher, 1988) and constitute a common symptom of several disorders classified as serious mental illness (Johns, Peters & Kuipers, 2007). They are broadly defined as beliefs that a person firmly holds which other people would consider unusual. Once characterized as “empty speech acts” (Berrios, 1991, p. 8), they are considered barriers to recovery and the success of the treatment is determined by their absence. Jaspers (1963) defined delusions as fixed false beliefs and identified certainty, non-understandability and incorrigibility as the three necessary attributes for qualifying an idea as delusional. The standard definition found in the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV-TR) adopted these attributes with the addition of a fourth criterion: a delusional belief is generally not shared by other members of a person’s culture or community (American Psychiatric Association; APA, 2000). Thus delusions are “erroneous beliefs that usually involve a misinterpretation of perceptions or experiences” (APA, 2000, p. 299). A belief is considered erroneous if it undoubtedly differs from commonly held beliefs and “if the belief is held despite clear contradicting evidence regarding its veracity” (APA, p. 299).

Critics of the psychiatric definition and its implications have contested the use of non-understandability or bizarreness as a criterion to define a delusion inasmuch as a belief is judged on the basis of the ideas and beliefs that the diagnostician holds (Kingdon, Turkington & John, 1994). This is further complicated when considering ethnic diversity and sociocultural context, which have been found to influence the delusional content (Butler and Braff, 1991; Serieux & Capgras, 1909; Suhail & Cochrane, 2002). In doing so a category of
psychopathology is created based on what one individual in a particular social milieu considers normal and acceptable thus obscuring “the enigma with which the deluding patient confront us” (Vanheule, 2011, p. 98). There is a risk of being blinded by the bizarreness of the belief to the detriment of an understanding of the individual, who “prior to becoming deluded will have had experiences, ideas, and attitudes that may render their abnormal belief comprehensible in some way” (Mullen, 2003, p. 548). Notwithstanding the objections, the psychiatric definition holds sway in mental health services and is part of the context service users experience in relation to their difficulties.

Recently, there has been a paradigm shift in understanding psychotic phenomena such as delusions (British Psychological Society; BPS, 2000). Within this framework, psychotic experiences and beliefs are meaningful and valid rather than symptoms of illness. Thus, far from being ‘empty speech acts’ delusions are psychologically understood within the context of a person’s life, circumstances and culture, and their attempts to find meaning in their experiences (Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002). This approach to understanding psychosis has paved the way for a more sophisticated understanding of delusions (Bentall, 2004a). Freeman and Garety (2006) have developed a multi-factorial account of their formation and maintenance. A key element is individuals’ appraisals of internal unusual experiences. This is consistent with psychoanalytic formulations, which regard delusions as responses to rather than symptoms of madness (Leader, 2012). They are attempts to ascribe meaning to the enigmatic phenomena of psychosis such as hallucinations by injecting a “fixed and determinate meaning into the place of perplexity” (Leader, p. 7). Their function is therefore considered intrapsychically restorative inasmuch as they are “applied like a patch over the place where originally a rent had appeared in the ego’s relation to the external world” (Freud, 1924, p. 151).
Recent models of psychosis implicate psychosocial influences such as adversity and trauma in its aetiology (Garety, Kuipers, Fowler, Freeman, Bebbington, 2001; Selten & Cantor-Graae, 2005). Research on the routes to psychosis has highlighted the role of trauma and stressful experiences (Freeman & Fowler, 2008; Read & Bentall, 2012) while the rekindled interest in the content of symptoms has inspired a body of research linking symptom phenomenology with childhood trauma (e.g. Reiff, Castille, Muenzenmaier & Link, 2012). This corroborates the conceptualization of delusions as kernels of historic and emotional truth, which warrant attention rather than eradication (Bentall, 2004a; Freud, 1938; Harper, 2004). Within the research literature, a couple of studies stand out. For instance, in a survey of 500 randomly selected residents in Mexico, sociologists Mirowsky and Ross (1983) found that paranoid beliefs were associated with exposure to victimization. They argued that social positions characterised by powerlessness and by the threat of victimization tend to produce paranoia. They found that powerlessness is associated with the belief that important decisions and results in life are externally controlled, rather than by one’s own resources. Beliefs in external control were strongly correlated with low socioeconomic status, ethnicity and being a female.

The persistent gender disparities in mental health are increasingly being recognised for example, by the recent publication of the World Health Association (WHO; 2012). Social and interpersonal factors such as poverty, victimization and sexual abuse are alarmingly higher in women while their status and life opportunities remain “tragically low” worldwide (WHO, 2012, p. 19). This means that women with mental health problems face particular risks and vulnerabilities due to the nature of their lives. In its guidance on Mainstreaming Gender and Women’s Mental Health, the Department of Health (DoH; 2003) acknowledges the specific needs of women not only in terms of the nature and prevalence of psychopathology, but also in terms of the reality of women’s lives, the context in which they
are embedded, their stresses and responsibilities that contribute to mental health problems. Concurrently, feminist writers such as Ussher (1991) have argued that women are positioned within the psychiatric discourse as mad while men are positioned as bad. The phenomenon of madness is a reality for many women and a focus on their mental health problems is relevant to a vast number of women (Appignanesi, 2008; Bartlett, 2003; Hustvedt, 2009).

Despite the fact that delusions are conceptualized as a problem of interpersonal experience (Boyd & Gumley, 2007) and “nearly always about individuals’ positions in the social universe” (Bentall, 2004b, p. 199), to date there has been no research examining their gendered nature. Also, while there is literature on the formation and maintenance of delusions there is very little that captures the perspectives of patients. Within the existing literature, several studies have utilized Grounded Theory (GT) to study psychotic phenomena (Boyd & Gumley, 2007; Coldwell, Meddings & Camic, 2011; Dilks, Tasker & Wren, 2010) and qualitative methodology is deemed suitable for first person perspectives. The present study aimed to address the gap in the literature by using a qualitative methodology to capture the accounts of women at different stages of their psychological difficulties who would thus constitute a diverse sample ranging from those who consider themselves recovered to those in the grip of delusions. It aimed to address the following research questions:

What are women’s experiences of unusual beliefs?

How do women make sense of their experiences of unusual beliefs?

How do women experience the response of others to the disclosure of delusional beliefs?

It was hoped that by knowing more about the process of women’s understandings and the impact of mental health services, a framework for understanding women’s specific needs could be developed from which initial clinical recommendations could be made.
Methodology

Participants

Ten women were interviewed. The main criterion for inclusion was past history or current presence of delusions irrespective of psychiatric diagnosis. Individuals with comorbid learning disability, substance/alcohol dependence and psychosis due to organic cause were excluded. All participants were in regular contact with mental health services and were recruited from various inpatient and community teams following their care coordinators’ approval. The first 7 participants had long histories of mental illness and contact with the services. The remaining 3 participants came from Early Interventions Services, which provide care for young people following their first episode of psychosis. Participants were considered by their care coordinators to be stabilized though most of them had ongoing positive symptoms of psychosis, including delusions. Three of them considered themselves recovered. Table 1 summarises the characteristics of participants.

Ethical Considerations

Ethics approval was obtained from an NHS Research Ethics Committee and Research and Development approval was obtained from an NHS Foundation Trust (Appendix B). The study adhered to the BPS (2006) and Health and Care Professions Council (HCPC, 2008) code of ethics and conduct. Owing to the vulnerability of the participants, issues of consent, capacity and risk were considered on an individual basis: All participants were in regular contact with the services and the researcher liaised with their care coordinators both prior to recruitment and following the completion of the interview process. In the event of disclosure of thoughts around death and hopelessness, the researcher used her clinical and interviewing skills to assess the risk. She also discussed with the participant her intention of informing the care coordinator before doing so. In the case of participants who were hearing voices, their content was explored through gentle questioning to ascertain the presence of command
hallucinations telling the individual to harm themselves or others but such material was not found. Apart from the moment to moment assessment of participants’ mental state during the interview, upon completion of the interviews each participant was debriefed and a conversation around the interview process itself was held to ascertain its potential impact. They were encouraged to make contact with their care coordinators and/ or the researcher, if they felt the need to do so.
### Table 1

Demographic Information of Participant Sample and Profile of Positive Symptoms of Psychosis

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age (years)</th>
<th>Employment</th>
<th>Ethnicity</th>
<th>Living Situation</th>
<th>Diagnosis</th>
<th>Psychotic Symptoms</th>
<th>Contact with services (years)</th>
<th>Admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>54</td>
<td>Homemaker</td>
<td>White</td>
<td>With partner</td>
<td>Bipolar disorder</td>
<td>N</td>
<td>&gt;20</td>
<td>2</td>
</tr>
<tr>
<td>P2</td>
<td>43</td>
<td>Unemployed</td>
<td>White</td>
<td>With partner</td>
<td>Paranoid Schizophrenia</td>
<td>N</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>P3</td>
<td>62</td>
<td>Unemployed</td>
<td>White</td>
<td>With husband</td>
<td>Paranoid Schizophrenia</td>
<td>Y</td>
<td>&gt;30</td>
<td>&gt;5</td>
</tr>
<tr>
<td>P4</td>
<td>50</td>
<td>Part-time</td>
<td>White</td>
<td>With partner</td>
<td>Paranoid Schizophrenia</td>
<td>Y</td>
<td>&gt;20</td>
<td>2</td>
</tr>
<tr>
<td>P5</td>
<td>47</td>
<td>Unemployed</td>
<td>Black</td>
<td>Independent</td>
<td>Paranoid schizophrenia</td>
<td>Y</td>
<td>&gt;20</td>
<td>1</td>
</tr>
<tr>
<td>P6</td>
<td>61</td>
<td>Unemployed</td>
<td>White</td>
<td>Rehab ward</td>
<td>Borderline Personality Disorder</td>
<td>Y</td>
<td>&gt;30</td>
<td>&gt;5</td>
</tr>
<tr>
<td>P7</td>
<td>33</td>
<td>Unemployed</td>
<td>White</td>
<td>With mum</td>
<td>Schizophrenia</td>
<td>Y</td>
<td>&gt;10</td>
<td>2</td>
</tr>
<tr>
<td>P8*</td>
<td>31</td>
<td>Voluntary work</td>
<td>White</td>
<td>With partner</td>
<td>Schizophrenia</td>
<td>N</td>
<td>&lt;5</td>
<td>4</td>
</tr>
<tr>
<td>P9</td>
<td>27</td>
<td>Full-time</td>
<td>White</td>
<td>With family</td>
<td>Paranoid Schizophrenia</td>
<td>Y</td>
<td>&lt;3</td>
<td>0</td>
</tr>
<tr>
<td>P10*</td>
<td>21</td>
<td>Part-time</td>
<td>White</td>
<td>With family</td>
<td>Paranoid Schizophrenia</td>
<td>N</td>
<td>&lt;2</td>
<td>1</td>
</tr>
</tbody>
</table>

* Considered recovered

*Hallucinations present
Design

The present study was qualitative using a semi-structured interview schedule. The open-ended questions used in semi-structured interviews are meant to open up rather than structure dialogue and they are likely to be modified depending on the emerging data (Elliott & Lazenbatt, 2004). This interview method facilitates the generation of rich data, required for constructivist grounded theory (GT; Charmaz, 2006), the chosen methodology for this study.

Procedure

Following presentation of the study to clinical team meetings, clinical staff identified individuals who they considered suitable to participate. Potential participants were approached by their care coordinators, who briefly described the study and provided the information sheet (Appendix C). Those interested gave consent for their care coordinators to pass on their contact details to the researcher. The researcher waited at least 24 hours before approaching the potential participants to discuss the project and make arrangements for the interview process. Consent was obtained from each individual at the start of the interview. To ensure informed consent, the purpose and procedure of the study were discussed, issues of confidentiality and participants’ right to withdraw at any time were highlighted (Appendix D).

The interview schedule was based on the research questions and was developed through service user consultation and drawing on relevant research in the area (Appendix E). A pilot interview was conducted with a member of the Salomons Advisory Group of Experts (SAGE) who commented on the choice and timing of the questions in terms of flow and comprehension, and interview completion within the time frame. Feedback was positive and the questions were reported to sufficiently address the research topic.
The interviews were audio-recorded and lasted between 45 and 90 minutes. The researcher transcribed each interview, taking approximately 6-8 hours each. A flexible approach to interviewing was adopted by allowing the conversation to unfold naturally. This meant that the key questions were not addressed in a particular order while in line with semi-structured interview practice certain responses were further explored to examine emergent themes. Consistent with GT principles after the first 6 participants were interviewed, recruitment was paused to allow for data analysis and to establish emergent categories by use of the constant comparative method. This was done to determine whether any of the questions needed to be altered as a means of directing theoretical sampling whereby any gaps in the properties that constituted the categories could be filled by subsequent interviews. Recruitment was then resumed and a further 2 interviews were conducted. This process was repeated a further 2 interviews were conducted to refine the categories.

Analysis

The data were analysed using constructivist GT (Charmaz, 2006), a more recent version of the original GT by Glaser & Strauss (1967). Charmaz’s version employs GT principles to “inductively distil issues of importance for specific groups of people”, in this case women with delusions, “creating meaning about those issues through analysis and the modelling of theory”, without subscribing to the objectivist and realist assumptions underpinning Glaser and Strauss’ work (Mills, Bonner & Francis 2006, p. 8). Consistent with social constructionism, constructivist GT assumes the relativism of multiple realities, endorses the co-construction of reality and meaning by the interviewer and the participant, and aims at understanding rather than explaining the studied phenomena and the subject’s meanings (Charmaz, 2003; 2006). The emergent theory offers “an interpretive portrayal of the studied world, not an exact picture of it” (Charmaz, 2006, p. 10).
The use of GT is most appropriate when little is known about the area of study and the generation of theory is the desired outcome (Henwood & Pidgeon, 2003; Strauss & Corbin, 1998). It has also been heralded as a methodology which endorses the goals and values of feminist research (Allen, 2011; Wuest, 1995). Given the dearth in the literature examining the process of women’s understandings of their delusions, the absence of theoretical conceptualizations of delusions specific to gender and the exploratory nature of this study, GT was deemed to fit well with the research question.

The interview transcripts were manually coded using line by line open coding. Consistent with Charmaz’s (2006) guidelines, gerunds were used in order to keep the focus of coding on processes and actions. This was followed by focussed coding whereby the most frequent and important codes were selected and raised to tentative categories. The first completed coded transcript and excerpts from two more of the early transcripts were checked by the academic supervisor. A study related peer group was used for further credibility checks during coding. Through the constant comparative method and memo writing, “the pivotal intermediate step between data collection and draft” codes and data were examined and grouped into categories (Charmaz, 2006, p. 72). Together with emergent themes they were examined in subsequent interviews for a more in-depth understanding of emerging categories. A decision was made not to use axial coding as it encourages the application of an analytic frame to the data thus restricting the coding process (Charmaz, 2006). Theoretical sampling began at the end of the first stage of data collection, after the sixth interview. By focussing on participants with long histories of difficulties it became clear that the data were restricted due to limited recall and vagueness in accounts, and experiences of care that may not necessarily have been reflective of current models of care. Therefore, active recruitment from the Early Intervention services was sought to shed more light on the emerging categories. Advanced memos were used to move to nascent analysis by establishing links
between categories and developing the argument. Consistent with Dey (1999, p. 257), “theoretical sufficiency” was preferred to theoretical saturation (Glaser & Strauss, 1967) as the aim of this study. Credibility of the findings was evaluated using Yardley’s (2000) guidelines.

Results

The data suggested that the process of women’s understandings of their delusions can be conceptualized and understood with reference to four generic themes or processes. These were: the process of women’s acquisition of knowledge about themselves and the barriers to it, significant life events, how women experience their delusions, and the process of emerging from the delusional world. These themes subsumed subtler processes illustrated in the categories and their properties in Table 2 below.

Summary of the model

The process of how women acquire knowledge about themselves and its consequences is central to understanding how they make sense of their delusions in the context of their lives (Figure 1). It mediates all other constitutive processes of the model. Inherent in the process of knowledge acquisition and the obstacles to this are women’s interactions with and responses of significant others. Hence in this model the core process of understanding is conceptualized as residing in the space between private experience and the social world. The delusional experience itself is understood as bifunctional: It operates as a means of coping with and compensating for earlier life experiences of loss and abuse of power. It also functions as a vehicle of externalizing ubiquitous and perpetuating cultural beliefs about gendered relational patterns. The process of emerging from the delusional world is a continuous negotiation of beliefs and the social, dynamically shaped by previous experience, evoked feelings and internalized stigma.
Table 2.
Themes, Categories and Properties of Proposed Model

<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
<th>Properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Process of and barriers to</td>
<td>Deferring knowledge to the other</td>
<td>Becoming transparent</td>
</tr>
<tr>
<td>acquiring knowledge about self</td>
<td></td>
<td>Being alienated from self</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Relying on feedback from others</td>
</tr>
<tr>
<td></td>
<td>Being shut down</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Making sense</td>
<td>Naming experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adopting the language of the other</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Being invalidated</td>
</tr>
<tr>
<td>Experiencing significant life</td>
<td>Loss</td>
<td></td>
</tr>
<tr>
<td>events</td>
<td>Abuse of power</td>
<td></td>
</tr>
<tr>
<td>Experiencing delusions</td>
<td>Constructing a new reality</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reinventing self</td>
<td>Taking centre stage</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Owning knowledge and certainty (3 dimensions)</td>
</tr>
<tr>
<td></td>
<td>Modes of relating</td>
<td>Becoming objectified</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Passive recipients</td>
</tr>
<tr>
<td>Emerging from the delusional</td>
<td>Managing disclosure</td>
<td></td>
</tr>
<tr>
<td>world</td>
<td>Experiencing feelings</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Internalizing stigma</td>
<td></td>
</tr>
</tbody>
</table>
Figure 1. A preliminary model of the process of women’s understandings of their delusions
Acquiring knowledge about self

Deferring knowledge to the other. The data suggested that acquiring knowledge meant to be curious about oneself. Curiosity was hampered by the process of deferring knowledge to the other while assuming a position of not knowing. A participant started by saying she did not know whether she had had delusions and she had to ask her partner to confirm this yet later on she said “obviously I was very delusional then” (P1). Participants disowned their knowledge and did not trust their minds. They turned to others to verify events. If they had learned to expect the other to speak on their behalf, to know what was good for them, to be the gauge of what was normal and what was strange then trying to explore their states of mind seemed redundant: “I can be really ill without realizing, my husband now . . . knows the symptoms to watch for, he can catch me get me more medication and get me more help really if it’s required”. (P1)

Becoming transparent. Women’s internal world was transparent: “and I went to the doctors as soon as I got back because I wasn’t right and everybody knew I wasn’t right, everybody knew I wasn’t well so I went to the GP”(P1). This was also reflected in delusional beliefs whereby they constructed an other who knew everything and became persecutory: “I think all the world knows me, people talking anywhere I go people looking at me talking about me and laughing, she is stupid she is crazy. I don’t know what has happened” (P2).

Alienated from self. The interviews indicated that when this other who ostensibly knew them was absent, they felt lost and alienated from themselves inasmuch as they did not know themselves. Thus, feelings of alienation could be aroused easily. They were in a state of “blankness” and “dying all the time” (P4), a wish to die inasmuch as they knew “all about life” and it was so boring (P2). But the terrain of subjectivising their experience was left
untouched. Confronted with a confusing experience, they felt so lost that a process of meaning making by means of the delusion unfolded:

It links to going back to prostitution to support my studies…It is a secretive job. . . I’d have strange comments made to me. . . So I became paranoid that people knew I was a prostitute. I thought my house was bugged because I couldn’t understand how they worked out what I was doing. . . . Not knowing used to make me feel uneasy. (P8)

*Relying on others’ feedback.* Women had learned to rely on others’ feedback and memory about themselves and thus constructed themselves through others’ words:

Probably I might have said a few things that could be that I was delusional but I didn’t know what I was saying, I couldn’t remember because when I was very ill. . . I can’t remember I couldn’t remember about that experience at all. . . It’s only kind of what I’m being told about it afterwards by other people (P1)

Similarly: “Nothing really helps me. The only thing is try to listen to what people say to me, and give me feedback” (P4).

The power of the words of someone in authority was so potent that they could turn to beliefs:

My dad said ‘everyone is talking about you, they say this is John’s baby, this isn’t your husband’s baby’ and I said that’s nonsense and I didn’t think anything of it. And then while I was talking to this doctor he said to me, in a roundabout way that Maria was John’s baby. So from then on I believed it. (P3)

**Being shut down.** Curiosity and the opportunity to gain knowledge about oneself were hampered by the experience of being shut down:

I: Why do you think you were not saying?
P: I don’t know. . . maybe he didn’t want to hear it, he didn’t like me being that way and he possibly didn’t want to hear. . . anything that was strange he didn’t want me to say. I remember him saying no don’t say that anymore you’ve said it enough so he didn’t want to hear anything strange coming from me so probably I didn’t say

I: You shut down

P: Yes, I think so, I think so because probably I couldn’t understand why he was getting so funny with me about it because I was saying something strange, something that he did not necessarily want to hear. . . and he’d say you said that last week so he wasn’t very good with that. . . I just remembered him saying that really. (P1)

However bizarre, repetitive and not true it sounds, the delusion has the status of belief. Having their beliefs silenced implied the sacrifice of participants’ own truth. In this process of submission to the other’s logic, they were deprived of a possibility for elaboration. Thus the repetition of the idea: “There is something wrong with my eyes” (P1), “my brain is dead” (P4). On both occasions these participants were advised to stop saying that; in fact, “to say anything but that” (P4). They stopped, but the idea did not go away. The former confined herself to the house while the latter learned to live alongside this belief forever alienated from herself, in a self-exile of a constructed “underworld. . . somewhere else to everybody else” (P4).

Making sense of experience. Participants were given a name for their experience, which sometimes pacified them: “People told me I have paranoia and it helped because I knew what was happening” (P2). It served to reduce the enigma of the experience. Alternatively, they did not identify with it: “People tell me I have schizophrenia, but I don’t think it is schizophrenia” (P3, P5).
Yet naming the experience did not imply an escape from the experience itself:

I started to speak to people but people don’t understand me (sic), they tell me you have paranoia, but I think this, they know all about my life…They told me it is my fantasy, but I do not know this word, I didn’t trust them, I think that what I think is the truth, people talk about me.  (P2)

*Adopting the other’s language.* Eventually participants adopted the language offered but without an opportunity to be heard and construct their own meaning, the reification of the experience left them with a feeling of resignation, boredom and lifelessness, which persisted. In this case, the fantasy world was more appealing:

I want to dream, my best time is when I dream at night-time, because I want stop my life; you know Hugo Chavez, he died and I’m jealous because he died and I just I want die, I want this all the time. (P2)

*Being invalidated.* The process of invalidation had sclerotic effects on the process of making sense of one’s experiences and oneself:

When I was due my husband called saying that ‘I think my wife is going to have the baby’, they said we don’t think she is, he said to me ‘you are not going to have the baby’ so I said ‘I’m sorry I think I am going to have the baby’ so I gave birth to the baby, he called them again, he said she’s had the baby so they were prejudiced again; another thing they were prejudiced they didn’t say ‘oh, we’ll come immediately’, they said, ‘we don’t think she is’! (P3)

Lack of validation could be felt as a threat to life itself: “In the end I thought my parents were trying to kill me . . . I would see people shuffling in graves . . . It was very scary” (P3).

Experiences of invalidation occurred subtly and repeatedly, feeding into earlier life events
marked by loss of self and perceived as a threat to oneself: “I ended up in hospital, which was a horrible experience, this place was like a concentration camp. They locked me up, they kept locking me up . . . I feel sure they were trying to gas me” (P3).

**Life Events**

My family were very overbearing; if I decided to do anything they’d be shouting at me . . . they would shut me down tell me not to do this not to do that . . . they did a lot of damage because they used to make such a big fuss of my sister that she was so brilliant and I am so stupid and I used to think I’m not stupid at all I’m more intelligent than my sister, she’s done some very silly things in her life. (P3)

**Loss.** The accounts of those women who could reflect on experiences before developing their beliefs converged on instances of loss ranging from loss of self in the form of invalidation as shown in the above quote (P3, P6) to loss of love (P2, P7, P8, P9, P10), of a job, which hitherto provided a “place in the world” (P6, P1, P4, P8, P10) and becoming homeless (P8) which resulted in the opening up of a gap that could not be filled:

It was mixture of things going on; losing people I cared about, not getting anywhere in my own life, losing direction, losing the job I did have and not being able to find anything to replace it with, constantly being rejected, which I have experienced a lot in my life. (P10)

Having an abortion (P6, P8) was also an experience of loss: “I was desperate because of the voices saying about an abortion I had when I was 19 calling me a baby killer” (P8).

**Abuse of power.** Such experiences were often coupled with experiences of abuse of power taking the form of ongoing sexual abuse, experienced by one of the participants, or different variations of emotional abuse:
I hadn’t spoken to mum for 12 years . . . She was very violent and mentally abusive. There was no love in the house at all. She was stabbing the door with knives, my brothers had to sleep with furniture behind the doors. (P8)

Similarly: “My father kept walking in and out of my life. I was like a kind of object that used to make him feel better about himself . . . He blamed me for everything that went wrong in his life” (P10).

**Experiencing delusions**

**Constructing a new reality.** Faced with such realities, constructing a new reality via the delusional experience became a way of coping:

So I found it hard to deal with; not getting anywhere, losing control and I suppose my mind came up with something I was in control, and it was a lot brighter, a lot happier; being the goddess of the universe . . . I made it to something like it was the greatest love of all; I used to believe that he was god and we were a couple creating life while in reality he had rejected me. (P10)

The interviews indicated that the participants who constructed manic states of heightened activity and omnipotence did so as a means of compensating for the pain of loss by not sacrificing any activity or relationship. Such states of no limits were inversely related to experiences of being silenced and shut down. Too much had been hitherto sacrificed and lost in the arena of personal voice and belief.

**Reinventing self.** While gripped by the delusions each participant became the architect and protagonist of an alternative reality, which could be either pleasant or distressing.

Taking centre stage. Irrespective of the associated distress, common to all women’s accounts was the placing of oneself centre stage in the self-constructed world they inhabited: “I am Virgin Mary and my daughter was injected, inseminated to me”. (P3)
And I’d look out of the window in the dark and I’d see a light go on . . . and thought unrealistically that they ‘d do that to taunt me. They know I don’t like the lights, I’m looking out of the window and they are turning it on on purpose to get me cross. (P1)

P: I’d go to the street, people hihi haha, people talking about me, my life. I thought all people know about my life . . . I think maybe you, [my nurse] knows me, like a superstar, you understand, all people know me.

I: So you think you are someone famous.

P: Yeah, famous but bad famous (sic). (P2)

Owing knowledge and certainty. Delusions qua beliefs meant that women were certain about what they knew and they knew what others wanted and thought. The delusional construction eradicated uncertainty and ambiguousness. In the case of persecutory delusions common to all but one participant, participants were sure that the other’s intentions were malicious: “I used to hang out with bikers and I approached them for help to get the bugs out and I thought they set me up for a shooting” (P8). They trusted their minds to make sense of things that had happened, to explain and convince:

So because he is like that, he pretends he is doing it to help them, but he is not. He just wants to stir things; but I know why now, I went back to my head again back in my past and I remember when I was 13 . . . But my uncle can’t look at me and the reason he can’t look me is because he knows I saw what he had done he knows I know he is a bad man . . . What he did was wrong and he is a bad man and I know in my head I know he don’t like my dad (sic) . . . so I now for a fact, I think it was him, I’m certain it was him, but I can’t prove it. (P5)

They knew what the other wanted, felt and thought:

My understanding is your minds connect so you are able to sense what they are thinking or feeling or they might say in their mind or you are able to hear it in your
own mind . . . So I suppose I have those beliefs that she was in contact with me telepathically. I was hearing her voice . . . She developed very strong feelings towards me, it wasn’t me having strong feelings towards her, and perhaps she still thinks of me and wants to have a relationship. (P9)

Meaning making was an integral process to knowing:

I had broken everything down so that numbers and letters meant different things, and I’d read car number plates continuously, it is constant, everywhere I look you are surrounded by car number plates and it means something different. I was always looking for clues as to what it meant, and would conjure up all these ideas as to what numbers and letters meant. (P8)

**Modes of relating.** The interviews indicated that when gripped by their delusions women’s realities were populated by people with whom they engaged in two interconnected ways:

**Becoming objectified.** When the delusion was persecutory women felt exposed and naked before the ever present gaze of a malicious other:

I had blinds in my room and I started [to] think people [were] watching me and [taking] photos [with] cameras and putting [them on the] internet . . . I had the fantasy [that] all people know about me, watching my life, know what I think, my things, and I just wanted to kill myself [that’s] what I felt. I felt naked. (P2)

Because he knew my dad was gone, he is always watching, watching the house, watching everywhere, my dad goes my mum goes he knows where they all are and he sent this person and the person came and abused my sister and then they left. (P5)

At times, this would lead to reconstructing a delusion precisely to put a limit to the intrusiveness of the other’s gaze and accompanying objectification by severing all ties even though at face value, the participant’s behaviour was a way of coping with her belief:
It was the start of my being. I can’t go out because my eyes hurt and I pulled down all the blinds to shut out the sun but then I didn’t like the dark either so I was in constant pain with my eyes. I was like that for a number of years. I stayed indoors for 8 years. (P1)

Alternatively, the presence of an intrusive other would be felt as a break-in:

Until this day it is a mystery how he entered the flat. It used to make me feel very uneasy. I quite often rang the police and reported the break-ins but actually I couldn’t prove anything because there was no proof of a break in. (P8)

Passive recipients. Gripped by the delusions participants found themselves in a weak position witnessing things happening to them. Often they were passive recipients of aggressive activity:

I take twice the dosage now cause . . . what they are doing to me, they keep digging and digging, and I keep feeling, men . . . in my pillow and talking to me in the night . . . I can feel their penis sliding up and down in my backside saying things to me, like, you are a dirty girl, that’s what they are saying and sliding up and down . . . It happens daily and it happens in the night, I’m not putting up with it really, coping with it, it seems like I am but I am not. (P5)

**Emerging from the delusional world**

Not all of the participants interviewed had emerged from their constructed world and the description of the subsumed categories reflects this variation.

**Managing disclosure.** Some participants had learned to live alongside their beliefs. They were accustomed to how they were received by others and had resigned to keep them private or manage the content:
I haven’t told anyone really . . . I told my daughter once, she just didn’t believe me she just thought I was mad, so I haven’t told my husband I haven’t told anybody else . . . I told people at the hospital. I think some of them believed me. But I didn’t say any details or anything else about it. I just said that Maria wasn’t my husband’s baby. (P3)

In turn, keeping beliefs private, accompanied by self-imposed isolation was a way that participants coped with their beliefs: “I never made any friends; I thought if I wasn’t close to anybody nobody could get hurt, it was still with me but it was manageable” (P6).

Other participants gave a more positive account of reactions by others and felt at ease to discuss their experience: “They were supportive, they wanted to know and tried to understand. It wasn’t difficult to talk to them” (P10). It was easier to talk to people who had had similar experiences:

I was very ashamed that I was hearing voices. I didn’t find it something I could talk about it at all. My main group of friends are all people I was in hospital with. . . I’m not ashamed about hearing voices and having delusions when my friends with bipolar and schizophrenia have all had these delusions and been through something similar. (P8)

The strategies employed in disclosing beliefs went hand in hand with experiencing feelings and internalised stigma.

**Experiencing feelings.** All of the participants who could reflect on the period of being acutely unwell, reported crippling feelings of shame, regret and self-blame: “If I hadn’t been ill I would have children I would have got married, no doubt about it” (P4).
If I had been given the medication then, it would have saved me two years of my life which I lost in isolation talking to myself and thinking I was going to be on my own forever. So I’ve lost a big chunk of my life . . . I was talking to myself continuously not being able to talk to others. I found that embarrassing as well” (P8).

Often the guilt and shame were reinforced by the other’s stance: “[My mother] feels I made a bid mistake reducing the medication and I feel that too, and I ruined my life. She has never forgiven me and 8 years since, she still refuses to talk about it” (P4).

Actually I went out without any clothes on once. . . I just had the Bible on one hand and I was walking down the street, I was looking for a chap I quite fancied. . . And of course it was my neighbour. . . who couldn’t come to me speak to me he told me afterwards he was just so astound by what he saw, he couldn’t do anything to help me so it had to be a complete stranger who took me back to my flat. (P1)

**Internalizing stigma.** This process was strongly associated with diagnosis as it was present in those women with a diagnosis of schizophrenia only. It would affect disclosure of beliefs: “I think it is too negative really what I’m saying and who wants to hear it noone wants” (P4). “When they told me I had schizophrenia, it scared me because it is a big word. Some people say they’ve got bipolar because it is more acceptable, there is a lot of stigma, sometimes you get funny reactions” (P10).

They were rather difficult they weren’t particularly kind, they would judge me. Another thing is at my GP surgery on my notes, on the top of the notes it says paranoid schizophrenic, it says, which isn’t very much patient confidentiality, is it? So every time the receptionist looks at that they see that written down. (P3)
Discussion

This study is the first to focus on delusions and women by examining the phenomenon through the lens of gender. The findings suggest that women’s experiences can be understood within the context of their lives and in particular their interpersonal transactions. Women’s capacity to gain an understanding of their experiences is influenced by their relationship to self-knowledge, which in turn is mediated by past and present interactions with others.

This is consistent with theories of women’s psychological development which place at their core the concept of the relational self (Chodorow, 1978). From this perspective, relationships with others are central to this “female psychological specificity”, shaping both their lived experiences and their sense of self (Stoppard, 2000, p. 63). Women measure their self-worth through their relationships and they will go at lengths to preserve these relationships “even if it exacts a terrible personal cost” (Aronson & Buchholz, 2001, p. 115; Williams, 2005). Indeed, findings from the present study suggest that women respond by silencing themselves after having suffered the pernicious effects of being silenced and invalidated, if not sexually abused. In this process, they lose track of their subjectivities while their femininity cannot be thought about. On this point, it is interesting to note that when asked about the effects of their experience on their identity as a woman, none of the participants were able to respond.

The study suggests that women construct an alternative reality via the delusion as a means of coping with experiences of loss, including loss of subjectivity. This is consistent with the conceptualization of the delusional function as a defence against the loss of self-esteem (Bentall, 2004a) and as “an attempt at recovery, a process of reconstruction” (Freud, 1911, p.71). Via the delusional mechanism they reinvent and authorize themselves to claim knowledge, certainty and control, attributes that they had hitherto relinquished or been led to
do so. An implication of the above is that owing to the nature of their lives, women are at greater risk of experiencing loss (e.g. at a basic level, the monthly menstruation) and may be prone to developing delusions as a defensive strategy or an explanation of enigmatic experiences felt in the body. This is consistent with research on delusions emphasising individuals’ appraisals of internal unusual experiences, which are then seen as attempts to ascribe meaning to enigmatic sensations as well as to the perplexing phenomena of psychosis (Freeman & Garety, 2006; Leader, 2012).

Interestingly, the assumption of attributes such as certainty and control via their symptomatic solution can be understood as a display of “reversed gender characteristics” observed in people with mental health problems (Krumm, Kilian & Becker, 2005, p.1536). In this process, the individual’s relationship to prevailing gender stereotypes is unfastened and atypical gender role behaviour is socially approved by dint of the psychiatric diagnosis. This might explain why female wards are seen as ‘louder’ and ‘aggressive’ compared to the ‘apathetic’ male wards (Showalter, 1985). If women’s lives have been replete with instances of silencing and invisibility then the delusional symptom sanctions the expression of unassailable authority and knowledge. This resonates with the observation of women’s resourcefulness in the face of oppression, which also prevents a gender specific analysis that resorts to a reductionist binary between weak women and domineering masculinities (Boyle, 1997; Ussher, 1991).

However, the findings suggest that when gripped by the delusions women engage in relational patterns which make them not only powerful through the possession of seemingly coveted attributes such as knowledge and authority, but also powerless through their positioning as objectified and passive recipients of the others’ whims. The experience of being exposed by the gaze of the other, unanimous in states of paranoia, can be interpreted as the epitome of gender-specific narratives in society whereby women are objectified,
positioned as commodities and objects of men’s desire (Ussher, 1991). It seems that in the grip of delusions a loosening of moral censorship occurs, which allows female participants to convey graphically the feeling of being in constant threat and their fear of being exploited. This is consistent with research findings linking vulnerability to paranoia particularly in women due to the nature of their lives (Bryer, Nelson, Miller, & Krol, 1987).

The emerging model aims to capture the perspectives of a diverse sample of women with a view to knowing more about the processes of understanding of their experiences of delusions and the impact of others on their understanding. It adds to the existing literature by offering a gendered perspective to current conceptualizations of psychosis, which acknowledge psychosocial influences but overlook an analysis of gender as a valid construct for mental health. For instance, prevalent biopsychosocial models of psychosis such as the cognitive model of the positive symptoms of psychosis (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001) focus on the cognitive mechanisms that turn internal anomalous experiences into psychotic symptoms and the maintaining mechanisms of such symptoms. Thus, biases in appraisal processes lead to an information gathering cognitive style characterized by jumping to conclusions, externalizing attributional biases, and deficits in understanding social situations and the intentions of others. While such a model acknowledges that these cognitive appraisals take place against a backdrop of environmental influences such as urbanicity and poverty, belonging to an ethnic minority group and social isolation, which have been found to increase vulnerability to psychosis, gender as a social construct that can increase vulnerability to or shed light on psychosis has been overlooked. Similarly, Gumley and Schwannauer (2006) have emphasised the interpersonal context and the impact of the wider social context on the aetiology of psychosis. They discuss the ramifications of urbanicity, migration and discrimination for engagement and recovery in psychosis and the role of stressful life events and early experiences of trauma however an
analysis of gender as a construct relevant to psychosis and mental health has hitherto remained unexplored. With its focus on women’s experiences, the emerging model contributes a gendered perspective to existing conceptualizations of psychosis by addressing this gap in the literature.

**Clinical Implications**

It is clear that women put a lot of emphasis on what is being said about them by others, particularly others in authority, especially when they are most vulnerable having lost faith in their own minds and judgment. Clinicians should be aware of the potential impact of their words and the risks of abusing the power their role carries. While being given a name for their experiences is usually helpful this needs to be accompanied by allowing and encouraging women to explore their experiences further so that they can create narratives and substantiate their sense of self. The construction of rich personal narratives has been found to be strongly associated with increased self-esteem, readiness to change and the quality of social connections among adults with schizophrenia spectrum disorders (Lysaker et al. 2006; Lysaker, Ringer, Maxwell, McGuire & Lecomte, 2010)

In acute states of illness, it is important that clinicians take orientation from what is being communicated via the delusion inasmuch as it is meaningful and consists of fragments of past significant interpersonal experiences as well as relational patterns that are gender specific. By knowing more about the meaning of the present symptom, repetition of similar traumatic encounters can be avoided. Similarly, clinicians should not be quick to challenge the belief as it serves an important reparative function in the face of an even worse affliction and may be the only resource women have at that point in time. Thus, before any treatment of the delusion as a sign of illness, it is important to understand its function. This is the first step towards the development of meaningful formulations and appropriate interventions.
Clinicians should be aware of the intense feelings such as shame and guilt that women may experience when emerging from acute state of illness as well as the tendency to hide those by isolating themselves and forming new symptoms guaranteeing self-exile; it is also important to remember that women may use isolation as a means of coping having lost their faith in being understood and lest they be characterised as mad. Given the importance women put on relationships, a tacit encouragement to open up, allowing time for this process to unfold is necessary. In so doing, they can be given the means to start to construct their own subjective history and create a narrative that is meaningful to them.

**Limitations**

The current model was constructed from the subjective accounts of ten women, primarily white-British, living in a particular geographical area. Only those women who were in regular contact with the services and willing to talk about their unusual beliefs participated in the study. Thus the model cannot be considered representative of women belonging to BME groups, with different sociocultural backgrounds or who are more socially isolated and harder to reach. Also, it is recognised that owing to the nature of the research and consistent with its findings about disclosure, what was shared was dependent on the context. Triangulation of results by interviewing care coordinators and checking notes would have been beneficial yet it would have reduced the “coherence” of the study, by deterring from the examination of women’s lived experience and understandings, which was its focus (Yardley, 2000, p. 222). Time and recruitment constraints contributed to a few limitations: A follow up interview that could have added to the richness of the data was not conducted while the process of theoretical sampling was restricted to changing the focus of the questions rather than actively looking for participants who would answer the emerging theoretical questions. In addition, member checking as a means of taking the ideas back to the participants for their confirmation did not take place. However, through the method of
theoretical sampling, categories were checked and refined with subsequent participants, a practice which is in line with quality criteria specific to GT (Charmaz, 2006). The results are going to be fed back to those participants who agreed on receiving a summary of the findings and it is hoped that in this way the constructed model will be further validated.

**Future research**

The gender-specific interpersonal context that psychological development in women is understood to take place and thus influence their personality development justifies a research agenda that recognises gender as a social construct intrinsically relevant to mental health. When the phenomenon of the genderless patient has been invariably cited as a cause of concern among people with longstanding problems (Celik, Lagro-Janssen, Widdershoven & Abma, 2011; DoH, 2003), a knowledge base that derives from women’s and men’s experience of the world is essential. The present study could be supplemented by research on women from BME groups and men’s experiences of delusions.

**Conclusion**

The constructed theory suggests that the process of women’s understandings of their delusions is mediated by the relationship they have to knowledge about the self, which in turn is mediated by the responses of others. Delusions themselves are understood as responses to life experiences of loss and abuse and thus are meaningful containers of truth. The model suggests that they manifest gender specific attributes, which can be understood in the context of women’s lives.
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Section C: Critical Appraisal

MAJOR RESEARCH PROJECT

PEGGY PAPADA BA (Hons), MA

WOMEN’S UNDERSTANDINGS OF THEIR DELUSIONS

Section C: Critical Appraisal

Word Count: 1993

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 develop further?

This was the first time I carried out a qualitative project and I found it a uniquely stimulating, but also an immensely challenging learning experience. Every stage of the research process required skills and abilities that I acquired as I was going along. These included selecting a topic, conducting literature reviews, writing a feasible research proposal, and selecting methodology, going through the NHS ethics approval process, liaising with teams and recruiting participants, conducting semi-structured interviews, analysing qualitative data and writing up the project. Some of these components are examined more closely below.

I felt grounded theory (GT) was a highly stressful and laborious process and often wondered whether it can actually be carried out successfully as an MRP, considering its aim for theoretical saturation and the tight time scale. Charmaz (2006) gives a number of 25 interviews as sufficient for a small scale project to claim category saturation, which is also dependent on the thorough analytic treatment of the categories. Yet, as time was running out I found myself closing things down rather than remaining open to further analysis of what was emerging. Given that proclaiming saturation rather than proving it is a common pitfall in GT research (Charmaz, 2006; O’Reilly & Parker, 2013), I was more comfortable with the concept of “theoretical sufficiency” whereby categories are considered to cope adequately with new data without needing further modifications (Dey 1999, p117).

For Dey coding can only be partial, which certainly resonates with my experience: Despite my initial apprehension to engage in open coding for fear I was not doing it properly, I soon
developed confidence in coding for processes rather than themes and topics. However, by the third interview and as I was becoming familiar with the data, I realized I needed to go back and correct the coding of previous transcripts. This process of recoding was repeated several times and I wondered whether it could ever end. Knowing that Charmaz (2006) would go back to her interviews over a period of forty years deflated me yet, accepting the limitations of my work was part of my growth as a researcher.

I decided to adopt a flexible approach to interviewing by not using my interview schedule actively as I felt it would disturb the flow of the interview process. The participants’ associations covered the basic areas I had delineated. However, when embarking on the analysis I was petrified by the vast amount of data that were not neatly ordered. It took me time to get a sense of what was going on while naively trying to create a priori order. I slowly embraced the uncertainty inherent in the analytic process, which I felt was one of the biggest challenges when working with the data; reading Charmaz advice to learn to “tolerate ambiguity but keep moving” assisted in allaying my anxiety (2006, p. 155).

Choosing the type of GT was not difficult as constructivist GT was close to my epistemological affinities of multiple realities and plurality of voices. I enjoyed the freedom and the agility it allows by using “guidelines to give you a handle on the material, not a machine that does the work for you” (Charmaz, p.115). However, the period during which I was immersed in the data, writing memos and developing them to more abstract ideas while also recoding and comparing instances and cases was a creative but also chaotic experience. Charmaz describes this process as “taking comparisons from data and reaching up to construct abstractions and simultaneously reaching down to tie these abstractions to data” (2006, p. 181). This was a process that required patience and openness inasmuch as in my pursuit for the abstract there was a risk of theorizing prematurely and overlooking important details.
2. If you were to do this project again what would you do differently and why?

Given the context of this project as a doctoral dissertation with specific requirements and a strict time-scale, I am not sure if it could have been carried out in a significantly different way. However, in response to this question I have some considerations: I would have aimed to complete my ethics application more quickly so that I had more time to dedicate to the recruitment and analysis stages. Despite the tediousness of the NHS ethics approval process, it was relatively straightforward for me and my tardiness and apprehension were possibly the result of being heavily influenced by negative experiences of other trainees in combination with the reputation of the process as dreary and cumbersome.

Also, had I had the flexibility to postpone the recruitment and interviewing of identified potential participants, I would have done so with a view to starting the process of theoretical sampling earlier than I did. In GT data analysis begins immediately after the first interview. However, considering the significant time I spent on transcription and the inconsistency of participant flow into the study (from weeks passing with no service user being referred to suddenly having four willing individuals to approach) together with the aforementioned tardiness in the coding process, my analysis started later than it would have been optimal.

Thus ideally I would have started the process of generating some tentative categories immediately after the first interview. Considering that theoretical sampling is what gives analytic impetus and direction (Charmaz, 2006), identifying categories earlier would have contained the painful stage of feeling lost by the volume of the data while being entrapped in an effort to describe everything that was going on. Lastly, in principle theoretical sampling is a process whereby particular information is sought, which can be obtained in a short period of time thus potentially offering the possibility of interviewing a large number of people. However, ethically I had trouble with this idea, particularly when aware of the journeys some participants had to make and their anticipation for the interview process, an opportunity to
tell their story. I was not sure how I could just obtain the necessary information and go without the establishment of the necessary rapport. I doubt if I would have changed this had I had a chance to do the project again.

All the interviews contained distressing material but some were particularly disturbing. I wish I had found better ways of dealing with it particularly when engaging in the lonely transcription process. Coming to terms with my blind spots as a listener, which I discovered while I was transcribing, was a disturbing experience and I wish I could have minimized its effects by having the possibility to go back to my participants to explore further. Ideally I would have included this in my ethics form; it would also have accommodated the process of “member validation”, which was not executed for similar reasons (Charmaz, 2006). Returning to the participants for a second interview would have also facilitated theoretical sampling and possibly assisted in richer accounts through further development of rapport. Yet somewhere a limit has to be drawn particularly when “the published word is not the final one, but only a pause in the never-ending process of generating theory” and interpreting the available data anew (Glaser & Strauss, 1967, p. 40).

3. As a consequence of doing this study, would you do anything differently in regards to making clinical recommendation or changing clinical practice, and why?

Listening to the transcriptions made me realise how much can be missed or even misinterpreted during a conversation; it highlighted the need to be more careful with assuming I have understood what the person is telling me and more curious about what is being said in between words. The findings supporting the psychosocial and gendered nature of delusions make me wonder whether psychotherapies such as CBT, which locate the problem within the individual can adequately address what is at stake here. There is a risk of overlooking factors that might be contributing to their distress and “illness” while awareness
of such factors could ameliorate women’s predicament by introducing practical interventions. For example, in acute care feelings of exposure could be toned down by ensuring that adequate clothing and bed linen are available as well as access to private space and female staff. Similarly, knowing the anxiety that the gaze of the other can provoke, a woman’s demand for isolation may not be a sign of madness or deterioration in mental health. However, I would be very aware of the use of isolation and silencing as coping mechanisms; acquiescence may have become just a way of being in her effort to get discharged, to not be perceived as mad or to not displease some significant other who wants her to say anything but what is true to herself; her belief, albeit delusional. Considering the above, therapy needs to offer the space for a formulation that is truly collaborative to emerge. It is so easy, particularly for us relatively inexperienced and enthusiastic therapists to impose our own understanding a bit too quickly in a bid for mastery and self-reassurance, yet what we might have heard might not even be half of the story. Women need to be empowered to develop their own narratives by a tacit encouragement that does not repeat the demands made upon them by the multiple roles they take in their lifetime.

Based on the findings of this study, delusions themselves can be seen as a way of remaining in the social bond, making sense of enigmatic phenomena and coping with experiences of loss. They therefore have an important function; eliminating the symptom without having provided the resources to do without it could be deleterious. Clinical interventions should not aim at challenging the delusion before having established its function. This of course, has implications for treatment with antipsychotic medication, which defines recovery on the basis of the absence of psychotic symptoms. Yet in the words of one of the participants: “They are stopping me from hallucinating, being paranoid and psychotic I suppose, stopping all that; they don’t take away the deadness, I suppose”. The risk implied is
further silencing and marginalisation whereas otherwise, we could establish our coordinates based on the delusion, what is being said, how it is being said and the patterns of relating.

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?

Through conducting this study, I learned about the epistemological affinities between GT and feminist research. I would therefore seek to extend the use of GT to questions in need of feminist exploration such as “the experience and lives of marginalized peoples, as they understand them” (Harding, 1993, p. 54). Mary Boyle (1997) noticed the absence of gender and social inequality from the theory and practice of clinical psychology owing to the discipline’s objective for scientific rigour; the scientific discourse makes no room for what is deemed as value laden and political. I was also sceptical about adopting a feminist perspective. Yet “the experiential, the private and the personal”, aspects of experience clinical psychologists as practitioners aim to capture and understand, are at the core of feminist exploration (Allen, 2011, p.25). They are often in opposition to male derived epistemologies striving for neutrality and truth. I would therefore continue work within a research agenda which acknowledges that findings are always contingent and incomplete but captures the diversity and plurality of voices (Allen, 2011; Charmaz, 2006).

That said, GT seeks to theorize and thus focuses on processes permeating participants’ accounts. However, in doing so some of the details particular to each individual are bound to be lost. For example one of my older participants spoke evocatively about the fact that there was no help as she was growing up and it was only recently when “the cupboard opened and everything fell out” that she started speaking only to be told that in her age she should not be self-harming. She raised the need for services to be compassionate for people of her age and what they might have gone through. Undertaking a case study would
have offered the in depth exploration of a particular experience thus noting the complexities stemming from the distinctive history and influences specific to that individual (Nock, Michel & Photos, 2007).

Overall, having gone through the entire GT process, I feel well equipped and more confident in pursuing further independent research on women with longstanding mental health problems, an inspiring, but neglected area of exploration.
References


Section D: Appendices

MAJOR RESEARCH PROJECT

PEGGY PAPADA BA (Hons), MA

UNDERSTANDING WOMEN’S EXPERIENCES OF PSYCHOTIC PHENOMENA

Section D: Appendices of Supporting Material

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY
Appendix A: Section A Search Methodology

A literature search was conducted including Cochrane Library, EBSCOhost, Medline, PsychINFO, Web of Science, Wiley as sources. The electronic databases were searched between January 1980 and April 2013. The search was expanded through reference lists and other available sources regarding a) women and psychosis and b) psychotic symptoms and childhood trauma history.

a) For the review of evidence on gender and psychotic symptoms (p.14) the following search strategy was used:

Gender OR sex AND psychotic symptoms OR psychosis = 461 papers

A manual examination of the cross-search results revealed papers irrelevant to the topic under review.

The search was narrowed by using “Gender differences” as a search term = 181 papers.

Results were searched manually. Studies which focused on symptoms other than positive symptoms of psychosis (n=18), comorbidities with drug/alcohol abuse (n=6), dementia studies (n=7), psychopharmacological studies (n=6) and studies with a solely biological/organic focus (n=44) were excluded. (For example, Chen, K. (2013). Striatal dopamine transporter availability in drug-naive patients with schizophrenia: A case-control SPECT study with [99m Tc]-TRODAT-1 and a meta-analysis. Schizophrenia bulletin, 39 (2), 378 -386.)

The remaining 100 studies were manually searched for relevance. Owing to the lack of focus on the review topic, the results were also supplemented with additional searches: Gender AND SMI OR Serious Mental Illness (n=26); women AND psychotic symptoms, NOT puerperal NOT postpartum (n=57)

Eventually, only studies with samples across the adult age range were reviewed and those which used gender as a paradigm for understanding psychotic symptoms (n=9).
b) For the review of evidence of adult psychotic symptom content and childhood trauma (p.19)

the following search strategy was used:

Content AND psychotic symptoms (n=240). This was narrowed by searching for: psychotic symptom content AND trauma (n=8). Studies which did not focus on childhood trauma were excluded. Not all studies were relevant. The search results were manually checked to find relevant literature. Studies were excluded if they described symptoms on the basis of DSM criteria/typology (for example, paranoid delusions, command hallucinations) without looking at the actual content. Eventually five studies were identified.
Appendix B: NHS Ethics and R&D approvals

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Appendix C: Participant Information Sheet

Participant Information for Service Users (v.2 30.09.2012)

Women’s understandings of their delusions in the context of mental health services and their lives: A preliminary model

My name is Peggy Papada and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in my doctoral research study. Before you decide, please read this information sheet carefully. It contains information about why I am doing the research and what it would involve for you. Talk to others about the project if you wish.

Ask me if there is anything that is not clear or if you would like more information. I will get in touch with you in the next couple of days to see if you are interested in taking part in the study and to answer any questions you might have.

What is the purpose of the project?
This is a research project which aims to explore women’s own understandings of their delusions. Delusions are broadly defined as beliefs that a person firmly holds but other people might consider unusual. I want to explore what kinds of beliefs these are, the life experiences that led you to hold these beliefs and the responses you received from others (for example, mental health services, friends and family) when disclosing and sharing such beliefs. I hope that increasing our understanding of women’s experiences of the mental health services and the social world in the context of delusional beliefs will result in better provision of inpatient and community care for women with similar difficulties.

Why have I been invited?
I am approaching women who have had experiences of delusions. The reason I am approaching you is because I am interested in understanding your experience from your point of view. I am focusing on women only as I believe that women have specific needs and complex issues that warrant particular attention.

Do I have to take part?
It is up to you to decide whether or not to take part. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive from your team in any way.

What will happen to me if I agree to take part?
If you agree to take part in my study, I will invite you to meet me for an individual interview, which may last between an hour and an hour and a half. You may take breaks whenever you wish. We can meet at [service name here] or somewhere else, if that is more convenient. Before we start the interview I will ask you to sign the consent form, agreeing to take part in the study.

In the interview I will be interested in asking you about your beliefs that other people may find unusual or you have been told that they are delusional. I will be asking you when you developed these beliefs and what was happening in your life at the time. I will also be interested in learning about the positive and negative experiences you have had since then. The reason for asking this is because I would like to know how your life experiences may have influenced your beliefs. Hence I will be particularly interested in learning about
your experience of other people’s reactions and responses to your beliefs and how these may have affected the way you see them. These could be responses from professionals, family and friends when disclosing and sharing such beliefs. There are only a few set questions as I am interested in listening to your personal account and understanding your experience.

You do not have to answer any questions that you find upsetting and you can have a short break, if necessary. At the end of the interview, if you wish you can speak to a key worker/member of the clinical team.

I would like to audio record our meeting so I can type up the interview later and make sure that I do not forget important information. The findings from your interview will be used to increase our psychological understanding of women’s experiences.

If you do decide to take part you will be reimbursed up to £10 for your time and travel expenses.

**What are the possible benefits of taking part?**
It is not expected the study will directly help with your care, although people often report talking to someone about their experiences can be rewarding.

**What are the possible disadvantages and risks of taking part?**
It is not expected that participation in the study has any risks; however, if you find any of the questions upsetting and would like to talk about this, please talk to your care co-ordinator or Doctor or contact the researcher: Peggy Papada (p.papada107@canterbury.ac.uk) or her academic supervisor: Dr. Louise Goodbody (Louise.Goodbody@canterbury.ac.uk)

Sometimes interviews may touch on areas that are sensitive for you or make you uncomfortable. You do not have to discuss anything that affects you in this way.

**What will happen if I don’t want to carry on with the study?**
You are free to withdraw from the study at any point without your care being affected in any way. If you withdraw from the study, I would like to use the data collected up to your withdrawal.

**What if there is a problem?**
If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to answer your questions (p.papada107@canterbury.ac.uk). If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details can be obtained from: Patient Advice and Liaison Service (PALS)

**Tel.**
You may also contact the research director at Canterbury Christ Church University:
Professor Paul Camic, Department of Applied Psychology
Canterbury Christ Church University
Salomons Campus
Tunbridge Wells, Kent TN3 0TG
E-mail: paul.camic@canterbury.ac.uk
Tel. 01892 507 773

Will my taking part in the study be kept confidential?
I will inform your clinical team that you are taking part in the study. Otherwise, all the information about your participation in this study will be kept strictly confidential. Under some circumstances, for instance if information that you told me led me to believe that you wanted to harm yourself or someone else or that negligence by a member of staff may have occurred, I would need to pass this information to a third party, and in the first instance I would discuss it with [redacted] to discuss what action may be necessary. The recording of the interview will be kept as electronic file and destroyed once the interview is typed. The typed interview will be kept securely and anonymously and will be identifiable only by a number, not by your name. Your name will be kept separately, with the number, so that I can identify your interview in the future if I need to (for example, if you decide you no longer want to be part of the study). I will only identify your interview for a reason like this. The typed interview will be kept securely in a locked filing cabinet in an office. All data use is strictly within the Data Protection Act (DPA 1998). In line with the policy of Canterbury Christ Church University your details will be kept for up to 10 years and then will be destroyed.

What will happen to the results of this research?
I intend to publish the results of the research. You will not be personally identified in any report/publication, however, anonymised quotes from your interview may be used in published reports. Should you wish to receive a summary of the results, please let me know and I will forward them to you when they become available.

Who is organising and funding this research?
I am organising and leading this research study in partial requirement of my doctorate in clinical psychology. It is funded by my training organisation (Canterbury Christ Church University).

Who has reviewed the study?
The study has been reviewed by the [redacted] (ref: [redacted]).

Further Information
Please contact me in the first instance if you have any questions or want to know more about the study:

Peggy Papada
Trainee Clinical Psychologist
Department of Applied Psychology
Canterbury Christ Church University
Salomons Campus
Broomhill Road
Tunbridge Wells, Kent TN3 0TG

Email: p.papada107@canterbury.ac.uk

You may also contact my lead supervisor should you have any further questions regarding the study:

Louise Goodbody
Year 2 Director,
Department of Applied Psychology
Canterbury Christ Church University
Salomons Campus
Broomhill Road
Tunbridge Wells, Kent TN3 0TG

Email: louise.goodbody@canterbury.ac.uk

Alternative Contact details
You may wish to contact the Patient Advice and Liaison Service (PALS), which provides information, advice and support for patients, families and carers. Although PALS will not have information about this study, they will be able to advise you on what participation in a research project might entail in general.

Patient Advice and Liaison Service (PALS)
Tel.
Email:

Thank you for taking the time to read this information sheet. I hope to be talking to you soon.

Best wishes,
Peggy Papada
Appendix D: Consent Form

Consent Form (v.2 30.09.2012)

Women’s understandings of their delusions in the context of mental health services and their lives: A preliminary model

Participant Identification Number for this study:

Researcher: Peggy Papada (Trainee Clinical Psychologist)

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<td>I confirm that I have read and understand the information sheet dated <strong>30/09/2012</strong> Version 2 for the above study.</td>
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<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without it affecting the standard of my care or my rights in any way.</td>
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<td>I understand that the interviews will be digitally recorded for the purpose of data analysis, and I hereby give permission for the interview to be recorded.</td>
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<td>I understand that the content of the interview is confidential as long as the researcher is not concerned about my safety or the safety of others</td>
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<td>I understand that any data or information used in any publications which arise from this study will be anonymous</td>
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<td>I agree to take part in the above research study.</td>
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<td>I wish to receive a summary of the results at the completion of the study.</td>
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Name of Participant ___________________ Date __________ Signature

Name of Person taking consent ________________ Date __________ Signature

When completed: 1 for participant; 1 for researcher; 1 for medical file.
Appendix E: Interview Guide

Version 2, 8th October, 2012

Draft interview guide for participants - -- In line with Grounded Theory methodology this guide is subject to modifications.

*The term “delusion” is used throughout as following consultation with members of the Salomons Advisory Group of Experts (SAGE) “unusual beliefs” is not a term they identify with as for them those beliefs, which others characterise delusional, are not unusual or bizarre.*

It is understood that any further questions the participants may have about the project have been answered satisfactorily at the beginning of the meeting and during the consent process and that the necessary rapport has been established before moving on to the questions below:

You know I am particularly interested in women who have had beliefs that other people might call “delusions” or “unusual beliefs” and you are interested in taking part in this study because you have had such beliefs. Can you tell me a bit more about them?

When did you first notice you had this belief? How did you come to believe this? What was going on/ happening in your life then?
(If the participant cannot recall/ identify the first time: can you tell me about a time you didn’t think that way? What happened subsequently that/ what do you think influenced you and led to you believing this? Additional Question added after Interview 6: How is it not to know?)

Who, if anyone, helped you with this belief? What did they do? What was positive/ negative about the way they responded to you?
Prompts for: family, friends, colleagues, teachers, mental health professionals.

Moving on, how, if at all, have your thoughts and beliefs changed since then? What do you think has contributed to this/ What experiences shaped your beliefs/ What positive changes/ events have occurred to your life / what negative events?

(If the participant cannot define change: can you tell me another time you held such beliefs strongly/ when others reacted strongly when you told them? )

Further prompts to be used, if necessary: can you tell me about the most recent experience that you believed this strongly? If applicable: think of your last admission to the hospital. What was helpful/ unhelpful regarding people’s responses to you?

How have others contributed to the way you’ve come to see these beliefs / Did you tell anyone? What did other people think and do when you disclosed such beliefs? Was it (their response) helpful?
Prompts: family, parents, partner, spouse, friend, professionals
After having such experiences what advice would you give to a woman who has just discovered she has delusions?
Is there anything else you think I should know to understand your experience as a woman with such beliefs better? How has your experience impacted you as a woman?

Additional Questions added after Interview 6:
Did you find it helpful to be given a diagnosis?
How did you deal with such feelings of shame and guilt?
How was it talking to people with similar experiences?
How do you make the choice of what to say and to whom? Why?
Is it important for you to be understood? What happens if you are not?
Appendix F: Audit Trail: Excerpts from Coded Transcripts

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Appendix G: Examples of Memos

Example of memos for the category of managing disclosure:

Memo “keeping beliefs private” (codes: not being understood; finding it difficult to explain; expecting she won’t be understood; worrying she will be considered mad; feeling lonely and isolated; being messed about/prejudiced against/not believed; keeping beliefs contained/ compartmentalizing; fearing hospitalization

Keeping beliefs private means that the individual chooses not to disclose her beliefs because she knows she won’t be understood and people will think she is mad.

She is reluctant to elaborate on her beliefs because “it is complicated and difficult to explain” but also because most people don’t believe a word she is saying.

She chooses not to talk to anyone about her beliefs really, because when she once spoke to her daughter, the daughter didn’t believe her and thought she was mad. Hence, she says she hasn’t told her husband she hasn’t talk to anybody else. The only people she shared these beliefs were the dr and staff at the hospital. However, she chose what to say: “I think some of them believed me. But I didn’t say any details or anything else about it, I just said that Helen wasn’t my husband’s baby”. Thus she disclosed what seems plausible but did not go to what is too “far-fetched” to be understood. Hence it seems that she manages to say something of her belief system yet not without censorship. She also tells people who are named professionals and in a position of authority.

During the interview she also chooses what to say and what to keep to herself. The silences are big and there is no elaboration. However, when she gives me a fragment of her world her speech is articulate, clear and her voice strong. It is also then that she asks me a question, my opinion about the state of the world hoping that I will confirm that it is getting better. In her delusion she can address her interlocutor. She also asks me whether I understand her. She occupies her place. In contrast, for most of the interview her speech is drained as if it takes a huge effort for her to speak and sometimes inaudible.

At times she feels very lonely as there are things that have happened in her life or things that she “believes hence they are true” that she hasn’t talk about to anyone, not even husband or children.

This choice of keeping beliefs private seems to have emerged since she was a child remembering her parents as believing her lies but not the truth.

Keeping beliefs private seems to go hand in hand with other instances of her subjective experience/speech/state being dismissed, discredited: She describes the traumatic birth of her daughter and how her husband called the hospital saying that his wife is about to give birth and the nurses wouldn’t believe this. Eventually she gave birth at home alone with her husband. She had an experience of the other disqualifying the signs coming from her own body on the basis of the fact that it wasn’t the right time. In her own words, she describes how many things have happened that she feels people are being difficult and prejudiced against her. She complains about patient confidentiality when she has seen “paranoid schizophrenic” written on her file in the GP practice, a diagnosis she does not identify with whatsoever.

She also has had the experience of not being heard and having her speech dismissed. This might not be pertinent only to beliefs but other descriptions of psychological states. For example she complained about the stress she was under with her children and the Dr dismissed her complaint saying that these are not symptoms of stress giving her medication, the answer to her complaints and telling her to “just go”
She is expecting she is not going to be understood, but she also knows it is very complicated for it to be understood: “it is hard to understand it is very complicated”. She also acknowledges her inability to explain: I can’t really explain, it is so far-fetched it is ridiculous however, this is was she believes, she doesn’t have to understand it yet she believes it hence it is true.

Theoretical sampling questions:

Q. Do you want to be understood?

Choosing what to say and to whom on the basis of what?

Memo – Disclosing beliefs

Disclosure of beliefs during the paranoid state very much depends on the content of the beliefs: A woman who felt responsible for the London bombings and believed she was wanted by the police and all criminal groups in London wouldn’t speak to anyone “I believed I was in trouble for something so I couldn’t talk to anyone. Her fear intensified as “when people were speaking I thought they were speaking about me threatening negative way I always felt under threat

However, she repeatedly appeals to whom stands for authority; either the police, the hospital all her former supervisors.

Another woman is certain that her uncle is organising crime. She wants to warn people against him, inform them about his activities so she collects and gives her evidence.

In the paranoid state, disclosing beliefs is spontaneous/ impulsive and its aim is to be rescued from the persecution. There is an appeal to the authorities, for example reporting the “break-ins” to the police even if there is no proof of a break in. There is an appeal to someone of a higher status that represents regulation and knowledge. “I emailed my supervisors letters of complaint about my experience on the ward…in details how they spiked my drink”

Having to see colleagues after a long time being off sick made her anxious; she has to choose what to say. What she says depends on how close a person is. She would laugh off experience

I felt anxious, anxious, anxious; after I had been off work for so long, six weeks, it was a long time to be off work and going back having to see all my mates at work and having to rehash the holiday, being silly,.ridiculous side ..what I choose to say, because it was a bit of a horrendous situation to talk about

P Where you able to speak to people about this

I think I just laughed it off and said that was the holiday , I laughed it off, I didn’t really go into great depth about it, not even with X at that point in time because we weren’t together, we were just mates , he was just a friend and we hadn’t got back together at that point

P You didn’t feel comfortable to talk

No I didn’t talk about , I didn’t talk about it to anybody, I just laughed it off it’s one of those things, what do you expect when you go away with that many people
A) Loss of identity/ self is managed through finding love in the face of a powerful man and being at the centre of attention

For this participant loss of identity was initiated when she came to this country with a male friend in order to escape the poverty that plagued her home country, leaving her family behind and not speaking the language. Soon after she started working as a cleaner and fell in love with the store manager, a married man who she believed was in love with her even though they never spoke due to language barrier. This lasted two years until he left the store. Female colleagues appeared to her as jealous and all colleagues were talking about them. She felt judged and exposed, feelings which developed into paranoia when he left, feeling that everybody knew about their love, feeling “naked” and unable to hide. Still, she described the two years he was around and who she would see on a daily basis as the best years of her life. Being in love with a powerful man seemed to cover the loss incurred by migrating. The subsequent loss of this (delusional) solution incurred paranoia, feelings of exposure and mockery. She felt they were cameras in her room and that she was in a reality show that everyone was watching, “taking interest in her life”; she was the subject or object of mockery and ridicule. It seems that on this occasion the loss of the object of love who had given her meaning and orientation in life, was covered by the others, everybody taking an intense interest in her life, however persecutory this was. Being preoccupied with others protected her from the radical loneliness of migration and subsequent separation from the love object.

Loving that man had stabilizing effects for her – losing love triggered paranoia

The medical intervention reduced the paranoia, gave her tools to understand her experience “it is your imagination” and appeased her. Since then she’s been left with a repetitive/automatic demand and wish to die because “life is boring”, there is nothing

B) Losing love propels her into paranoia

Participant 002 is someone who identified becoming unwell when she came to this country. She didn’t speak the language at all, she had no family apart from a male friend (who sounds like partner) with whom she has been living since then and who sounds very supportive. Shortly after coming here she started working as a cleaner and fell in love with her boss. She describes these two years that she was in love with the store manager as the best two years of her life. This was accompanied by feelings of paranoia and “everybody” knowing about them, looking at her, calling her stupid etc and culminating in hospitalization because she wanted to kill self. When he left/changed jobs her turmoil increased with paranoia escalating feeling exposed and “naked” and 8 years on with medical interventions, she feels life is boring, repeating she wants to die though not wanting to kill self. It feels as if her paranoia kept her busy, was at the centre of her world. People were interested in her and thus veiled the loss, lack and isolation. We could say that falling in love with a powerful man, in a way that seems erotomanic and platonic gave her an identity, a purpose, channelled her desire and found meaning in life. The happiest years of her life despite being in a foreign country not speaking the language and being isolated.

Here is a case of a woman suffering because of her isolation in this foreign country and the inability to fulfil her wish and go back to her country owing to the poverty there. Her family encourages her to stay where she is; when the first needs cannot be met how can one look at the psychological needs.

There is something in the repetitiveness of her demand “I want to die”, life is boring, do you understand” I want things to stop, nothing”. It is repetitive, automatic,
There is a language barrier and at times she seems to have adopted the language of the other. This is my fantasy, it is not true, she says, only to confirm that this is what the Drs told her when she went to the hospital. Removing the symptom of paranoia results in wanting to die.
Appendix H: Excerpt from Research Diary

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Appendix I: Summary letters to Ethics Committee and Trust R&D

Dear REC panel,

Re: Study title: Women's understandings of their delusions in the context of mental health services and their lives: A preliminary model.

REC reference: [redacted]

Please find enclosed the final report summary of the above research study, which you approved on [redacted].

Thank you for reviewing the project and do not hesitate to contact me should you need any further information.

Yours sincerely

Peggy Papada
Trainee Clinical Psychologist

Canterbury Christ Church University, Salomons campus
Broomhill Road, Tunbridge Wells
Kent
TN3 0TG
Dear [Trust Address],

Re: Study title: Women's understandings of their delusions in the context of mental health services and their lives: A preliminary model

I am writing to inform you that the above study, which you approved has now been completed. Please find enclosed the final study report summary.

I will be returning to the recruiting teams to disseminate the findings as clinical recommendations regarding women with experiences of psychotic phenomena are made.

Thanks again for hosting this research study.

With best wishes,

Peggy Papada
Background. Psychotic phenomena such as delusions have recently been psychologically understood as meaningful within the context of a person’s life while recent models of psychosis implicate psychosocial influences in its aetiology. Research on women with such experiences has been limited despite recognition of their specific needs and vulnerabilities due to the nature of their lives. This study aimed to examine the processes influencing women’s understandings of their delusional beliefs in the context of their lives.

Design & Methodology. The present study was qualitative using a semi-structured interview schedule. A social constructionist version of Grounded Theory was used to conceptualize the process of women’s understandings.

Potential participants were identified by their care coordinators. Ten women who had experience of delusions were interviewed.

Results. Grounded theory analysis suggested that the process of women’s understandings of their delusions can be conceptualized and understood with reference to four generic themes or processes: Women’s acquisition of knowledge about themselves, significant life experiences, how women experience their delusions, and the process of emerging from the delusional world.

Conclusions. According to the constructed theory, the core process of understanding is conceptualized as residing in the space between private experience and the social world. It is mediated by the relationship women have to knowledge about the self, which in turn is mediated by the responses of others. The delusional experience itself is understood as bifunctional: It operates as a means of coping with and compensating for earlier life experiences of loss and abuse of power. It also functions as a vehicle of externalizing ubiquitous and perpetuating cultural beliefs about gendered relational patterns. Hence, delusions are understood as responses to life experiences and are therefore meaningful containers of truth. They manifest gender specific attributes, which can be understood in the context of women’s lives.

Implication for services

- Women should be encouraged to explore their experiences further so that they can create narratives and substantiate their sense of self.
- Women silence and isolate themselves as a way of coping. Clinicians should allow space for verbalization through the gradual establishment of the therapeutic relationship.
- Clinicians should be aware of the impact of their words owing to their position of authority and the risks of abusing the power such a role carries.
- Clinicians should not be quick to challenge the belief as it serves an important reparative function in the face of an even worse affliction and may be the only resource women have at that point in time. Thus, before any treatment of the delusion as a sign of illness, it is important to understand its function.
- Gender is a social construct particularly relevant to mental health. Clinicians should be aware that behind the “genderless individual” – a disconcerting phenomenon among people with longstanding mental health difficulties – there lies a woman and a man whose experience of the world is very different and is worthy of attention. If we are to provide formulations that are meaningful to them.
Appendix J: Journal Submission Guidelines

Psychology and Psychotherapy: Theory, Research and Practice

Edited By: Andrew Gumley and Matthias Schwannauer

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Author Guidelines

Psychology and Psychotherapy: Theory Research and Practice (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

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