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Meta-synthesis of qualitative studies of psychosis 2

Abstract

Qualitative studies have played an important role in elucidating the lived experience of

psychosis and there has recently been an increase in the number of such studies. There is

now an urgent need to draw together the findings of these studies. This paper performed a

meta-synthesis of inductive qualitative peer-reviewed research into psychosis. Ninety-eight

articles were identified for systematic appraisal. Four themes, 'Losing', 'Identifying a need

for, and seeking, help', 'Rebuilding and reforging', and 'Better than new: gifts from

psychosis', were identified. The important implications these themes for clinicians and future

research are examined upon. These findings also highlight that the experience of psychosis is

much more than simply just hallucinations and/or delusions.

Keywords: Human needs, recovery, schizophrenia.

The past decade has seen the emergence of a significant body of research that seeks to explore individual's experience of psychosis. Methodologically, qualitative research is most suited to this aim, and in particular inductive qualitative research whose findings are derived primarily from in-depth 'data' derived from engagement with individuals (Willig & Stainton-Rogers, 2008). The findings from these qualitative studies of psychosis offer a rich and deep source of information that can help mental health professionals understand their client's experiences.

A limitation of individual qualitative studies of psychosis is the extent to which they actually influence policy. Studies may lack impact due to their very nature of being rich individualized accounts or concerns over their generalizability (Morse et al., 1998). Walsh and Downe (2005) have highlighted the danger of such research being marginalised by policymakers and clinicians if there is no attempt to connect between studies. One way to address this is through meta-synthesis, a technique which aims to make qualitative findings more accessible for practical application by amalgamating individual studies (Zimmer, 2006), and which may also help create new knowledge through identifying new overarching themes. This paper aimed to perform a meta-synthesis of peer-reviewed inductive qualitative research into lived experiences of psychosis. In doing so it attempted to formalise and re-conceptualize themes from these studies to create new, more broadly applicable knowledge of the meaning of psychosis, likely to be of direct use to mental health professionals, policymakers, and service-users themselves. The selection of inductive qualitative studies involving systematic analysis of first-hand accounts was not intended to suggest a superiority of these studies either over other research designs, but simply to provide an understanding of a specific section of literature that has a unique, but not comprehensive, contribution to make to the understanding of psychosis and how individuals relate their experiences.

### Method

Inclusion criteria were that the study should be an inductive qualitative study of some aspect of psychosis, be based on analyses of first-hand accounts by the person with psychosis, and be published in an English language peer-reviewed journal between January 2000 and May 2010. Exclusion criteria were that the study was a single person case-study, an ethnographic study (e.g., solely based on participation/observation), or if it lacked evidence that its conclusions reflected inductive analysis grounded in the data. We limited our review to post-January 2000 to generate a quantity of information that was practically synthesizable and also to acknowledge that changes in society and practice may lead experiences of psychosis to differ in different eras.

Relevant papers were identified by a search of the MEDLINE and Scopus databases. The search string employed was: (schizophren\* OR psychosis OR psychotic OR hallucin\* OR delusion\*) AND ("in-depth interview" OR qualitative\* OR interpretive\* OR transcribe\* OR "focus group" OR "grounded theory" OR hermeneuti\* OR open-ended OR narrative\*). Reference sections and citation reports from the papers selected for inclusion in this paper were also examined. This search identified 2,635 potentially relevant papers. The abstracts of these papers were then examined. We initially erred on the side of inclusiveness when identifying relevant qualitative literature (Dixon-Woods et al., 2007), identifying 175 papers as potentially relevant. The full-texts of these papers were re-examined in detail and the formal inclusion/exclusion criteria applied. This led to the exclusion of a further 77 papers, leaving 98 papers for inclusion. A descriptive table of these studies is available from the authors on request. Although the quality of papers varied widely we did not feel it necessary to exclude any of these papers on grounds of quality.

We followed the method of analysis outlined by Walsh and Downe (2005), beginning by identifying what we perceived as key metaphors, phrases, ideas, and concepts in each

study, adding our own words or paraphrases. These were then sorted into broader themes. The next stage was reciprocal translation, in which we tried to transpose the findings of an individual study into those of another, using metaphors and concepts that were applicable to both, whilst being careful to make sure that differences were not glossed over or subsumed. Finally, translated concepts were synthesized to elucidate more refined meanings, exploratory theories and new concepts.

Validity of themes was addressed by having initial themes developed independently by two of the researchers. These were then critically explored, and modified through discussion with the other authors. We addressed internal validity by including original quotations from respondents, and external validity by triangulating our findings with the quantitative literature. A reflexive approach was taken throughout the study by considering how our own training, theoretical positions and personal beliefs were likely to impact our analyses.

#### Results

The 98 studies synthesised had a total of 1,945 participants (M = 19.92, SD = 22.77). Of the studies that reported specific data on age and gender, there was a mean participant age of 34.48 years (SD = 9.00) with 55% of participants being male. The ratio of studies that used first episode patients or patients from early intervention services to studies that employed older, more chronic patients was approximately 1:3. Four themes relating to the experience of psychosis were inductively generated.

# Theme 1: Losing

This theme centred on the devastating losses psychosis can result in, ranging from the loss of the very existential ground under one's feet, to the loss of the people in one's heart. *Sub-Theme I: The loss of consensual reality* 

After initial prodromal changes such as "a feeling of being uncomfortable and something just not being right" (Shea, 2010, p. 46), psychosis is dominated by confusing, unshared perceptions (voices, visions) and/or paranoia (Hirschfield et al., 2005; Dilks et al. 2010), which can be highly heterogeneous (Karlsson, 2008; Garrett & Silva, 2003). Such experiences often lead to a feeling of being in a different reality (Dilks et al., 2010; Gould et al., 2005; Mauritz et al., 2009; Jarosinski, 2008), accompanied by feelings of confusion and fear (Barker et al., 2001; Boyd & Gumley, 2007; Boydell et al., 2006; Geanellos, 2005; Killikku et al., 2003; Robertson & Lyons, 2003; Shea, 2010). Yet individuals are not typically suicidal at this stage as they are absorbed in dealing with their experiences (Skoldlar et al., 2008). This fear often remains, or is amplified, by hospital admission (Laithwaite et al., 2007). Positive aspects of the experience may also exist, such as a feeling of connection with the universe (Kinderman et al., 2006; Nixon et al., 2010a).

Sub-Theme II: The loss of self

A theme of lost facets of the self was identified. Firstly, a loss of the sense of having a coherent self is frequently reported (Geanellos, 2005; Kinderman et al., 2006; Koisvisto et al., 2002; Moller & Husby, 2000; Nixon et al., 2010b, Robertson & Lyons, 2003; Roe, 2005). As one participant put it, they experienced "distance to or loss of myself" (Moller & Husby, 2000, p. 223).

Self-esteem can be lost due to the content of voices and delusions (Rhodes et al., 2005), loss of employment (Bassett et al., 2001; Mackrell & Lavender, 2004) and labeling/stigma (Laliberte-Rudman et al., 2000; Lloyd et al., 2005; MacDonald et al., 2005; Rice, 2008). This is often internalized resulting in participants judging "themselves as useless, incapable or insane" (Wagner & King, 2004, p. 143). Participants report being labeled as freaks (Chernomas et al., 2000), dangerous (Gonzales-Torres et al., 2007; Schulze et al., 2003) and being made to feel "like a different species" (Laliberte-Rudman et al., 2000,

p. 140). These feelings of inferiority are a reason for suicidal ideation in many patients (Skodlar et al., 2008). Loss of autonomy creates a feeling of lost respect (Krupa et al., 2010; Stein et al., 2001; Wagner & King, 2004; Warren & Bell, 2000), with participants resenting decisions being made for them (Humberstone, 2002; Lloyd et al., 2005), and experiencing a sense of mystery around these decisions (Carrick et al., 2004).

One's self-identity can also be lost, with diagnosis being associated with a change in identity (Pitt et al., 2009), such as a "dehumanizing and devaluing transformation from being a person to being an illness... to being 'a schizophrenic'" (Dilks et al., 2010, p. 98). Sideeffects of anti-psychotic medication can also lead to changes in both self-identity and selfesteem, often through weight gain and sexual dysfunction (Johnstone et al., 2009; Laithwaite et al., 2007; Roe et al., 2009).

Clinicians may also damage patient's self-esteem and self-identity (Bassett et al., 2001), making them feel like guinea pigs (Rofail et al., 2009), or treating them "like a little child, they can treat me like a spastic, they can treat me like a nothing" (Humberstone, 2002, p. 370). Participants can report a lack of interest in them as a person (Cook et al., 2009; Killiku et al., 2003; Schon et al., 2009; Schulze et al., 2003; Warren & Bell, 2000), and experiencing a focus on symptoms and medication (Tooth et al., 2003); "you are now a schizophrenic and we treat you with medication" (Thornhill et al., 2004, p. 188). Participants also may feel their needs and perspectives are not taken seriously when making somatic complaints (Chernomas et al., 2000; Gonazles-Torres et al., 2007; Schulze et al., 2003).

Finally, what could be termed a loss of self-actualisation opportunities is also found, through a loss of meaningful activities and thwarted potential and growth opportunities (Wagner & King, 2004; Gonzlaes-Torres et al., 2007; Krupa et al., 2010).

Sub-Theme III: The loss of hope and motivation

Hope is frequently reported as lost. The loss of a viable future is a key reason for this (Knight et al., 2003; Gee et al., 2003; Rice, 2008), particularly if patients lose their jobs (Perry et al., 2007) or have their children taken away (Diaz-Caneja et al., 2004). Hallucinated voices can reinforce this hopelessness (Jarosinski, 2008). The mental health system can lead to loss of hope through biological determinism (Thornhill et al., 2004), pessimistic attitudes towards reemployment (Chernomas et al. 2000; Marwaha et al., 2004) and recovery (Tooth et al., 2003), and diagnosis (Judge et al., 2008; Pitt et al., 2009; Wagner & King, 2004) particularly when communicated in the form of "You've got schizophrenia, you will be ill for the rest of your life" (Schulze et al., 2003, p. 304). Loss of hope often leads to a depressed, demotivated state (Bassett et al., 2001; Gould et al., 2005; Laliberte-Rudman et al., 2000), with one participant when asked what they saw themselves doing in the next five years, simply replying "nothing" (McCann & Clark, 2004, p. 789).

Sub-Theme IV: The loss of security in body and world

The security of a reliable body may be lost, with a loss of physiological homeostasis including altered sleeping patterns (Gee et al., 2003; Geanollos, 2005; Laithwaite et al., 2007; Nixon et al., 2010b), eating patterns, and new somatic pains (Koivisto et al., 2002). Medication side-effects also impact upon physiological homeostasis, potentially increasing appetite and sleep (McCann & Clark, 2004; Rofail et al., 2009), and causing physical pains (Roe et al., 2009); being "like hell... like a screw being tightened in your brain" (Usher, 2001, p. 148).

Loss of security in the world is also seen. Participants can feel directly under attack from psychotic experiences such as voices (Boyd & Gumley, 2007); "it just won't let you lie there and rest... they're at you 24 hours of the bloody day" (Abba et al., 2008, p.81). Hospitals may also be feared (Koivisto et al., 2004), with some participants using "imagery about imprisonment and torture" (Thornhill et al., 2004, p. 188). Participants often lose jobs

as a result of psychosis (Gee et al., 2003; Woodside et al., 2008), with symptoms being too severe for them to carry on working (Nithsdale et al., 2008; Sung et al., 2006). This means a loss of financial security, with large debts potentially building up (Krupa et al., 2010). This can then impact adversely on participant's living arrangements (Browne & Courtney, 2005b; Laliberte-Rudman et al., 2000), creating eviction fears and a loss of personal safety; "I got raped one night, no-one came, even though I screamed" (Warren & Bell, 2009, p. 198). *Sub-Theme V: The loss of relationships and the pain it causes* Psychotic experiences can lead to self-imposed isolation (Gee et al., 2003), with withdrawal being used as a coping mechanism (Judge et al., 2008). However, isolation may also be due to the actions of others. For example, many participants talk about the loss of relationships with friends and family who don't understand what they are going through (Chernomas et al., 2000; MacDonald et al., 2005; Robertson & Lyons, 2003; Wagner & King, 2004). Stigma and discrimination can cause of the loss of many relationships (Gonzales-Torres et al., 2007; McCann & Clark, 2004; Schulze et al., 2003), as can as medication through side-effects impairing social relationships (McCann & Clark, 2004; Usher, 2001). Psychosis can also form barriers to romantic relationships (Bassett et al., 2001; Chernomas et al., 2000; Redmond et al., 2010) due to a lack of resources such as confidence, energy, and friends (Redmond et al., 2010) and housing (Warren & Ball, 2000). Psychosis also profoundly impacts on sexuality, due to problems including medication-related weight gain (Volman, 2007) and medication-related sexual dysfunction (Chernomas et al., 2000; McCann & Clark, 2004). Sex for the purpose of reproduction is often discouraged; "You mention to the psychiatrist that you want to have a child and he says 'no, that's not possible, don't even think of it" (Gonzalez-Torres et al., 2007, p. 19), which many patients later regret

(Chernomas et al., 2000).

Another key relationship that may be negatively affected is that between the patient and their children. Both mothers and fathers may worry that their children could develop a mental illness due to genetic factors (Chernomas et al., 2000; Diaz-Caneja et al., 2004; Evanson et al., 2008). Mothers are concerned at having to cope with both with their children and their mental health problems, and afraid that their children may be taken away from them or that services would not allow their children into hospital to see them (Chernomas et al., 2000; Diaz-Caneja et al., 2004).

The loss of relationships cause great suffering (Wagner and King, 2004) and loneliness (Mauritz et al., 2009; Schulze et al., 2003); "the trouble with schizophrenia was loneliness" (Humberstone, 2002, p. 369). This pain is felt particularly acutely, since this is typically a time where the need for love and belonging is especially strong (Wagstaff et al., 2007). Such loneliness can lead to suicide (Skodlar et al., 2008).

Theme 2: Identifying a need for, and seeking, help

A theme was noted of a transition phase from believing one was having unusual but still potentially manageable experiences, to finding one needed help and that this was available. Some participants initially think their psychotic experiences will spontaneously resolve themselves and deny there is a problem (Boydell et al., 2006). Others try to endure their symptoms for a while (Ko et al., 2006), but most choose to seek professional help when their symptoms worsen and they can no longer cope (Hardy et al., 2009; Killiku et al., 2003). One reason for not entering the mental health system earlier was the perception it is something "to be survived rather than services that facilitated survival" (Humberstone, 2002, p. 370).

Studies note that before seeking or receiving treatment participants "must first develop some degree of acceptance of their illness" (Usher, 2001, p. 149; Roe et al., 2008). Reasons for believing oneself to be ill include seeing what happened when not on medication (Ko et al., 2006; Usher, 2001). Attributing experiences to an illness can be hard (Roe et al.,

2008), with one patient reporting that "I'm considering that it might be the medication [making me better]. In that case I've got to start believing that it wasn't demons. And I find that hard to believe" (Drinnan & Lavender, 2006, p. 324).<sup>1</sup>

### Theme 3: Rebuilding and reforging

A theme was identified of patients seeking to rebuild and reforge the self and world that psychotic experiences had caused to be lost.

Sub-Theme I: Rebuilding and reforging reality and self

Once the "fear and confusion of fragmentation" has passed (Geanellos, 2005, p. 12), a sense of a stable, understandable reality can be regained. This reality may still involve hearing voices, but is one in which they can be dealt with better (Costain et al., 2008). Many studies (although not all) find medication helps this process by increasing feelings of reality and enabling clear thinking (Rofail et al., 2009; Usher, 2001). Praying and meditation are reported as helpful by some participants (Sanseeha et al., 2009). As part of this process confusing, senseless experiences may be transformed into understandable, meaningful experiences. Although in the acute phase of psychosis, attempts to explain the experiences often leave patients more confused (Campbell & Morrison, 2007; Kinderman et al., 2006), when recovery is underway participants try to make sense of their experiences, potentially aided by psychosis support groups (Hyde, 2001). Some link their experiences to abuse and other traumatic experiences in childhood and other stressors (Carrick et al., 2004; Holzinger et al., 2003; Nixon et al., 2010b). Other explanations include genetics, changes or losses in social networks, neurotransmitter imbalances, financial problems, society, loneliness, drugs,

<sup>&</sup>lt;sup>1</sup> It is worth noting that some individuals with psychotic experiences may not require help nor seek it.

spirits, or that psychosis was a warning of something wrong (Barker et al., 2001; Drinnan & Lavender, 2006; Holzinger et al., 2003; Karlsson, 2008).

This sense of a coherent reality allows the regaining of a coherent self within this reality (Jarosinski, 2008; Schon et al., 2009). This can be aided by mindfulness (Abba et al., 2008), and detachment/distance from experiences (Nixon et al., 2010b; Roe et al., 2004). Yet, rebuilding the self is a delicate time (Shea et al. 2010), with a sense the regained self and reality can be lost again, and of "not being confident with your own mind. Knowing that you can lose it, as it happened before" (McCann & Clark, 2004, p. 788).

Once a sense of having a self is regained, this can be built on by regaining a selfidentity and a sense of self-esteem. Self-identity can be regained, for example, by asserting a unique individual identity (Humberstone, 2002), work (Kennedy-Jones et al., 2005), or the re-discovery of an old talent (Roe et al., 2005). In terms of regaining self-esteem, work appears to be particularly helpful (Dunn et al., 2008; Sung et al., 2006; Kennedy-Jones et al., 2005; Liu et al., 2007; Marwaha et al., 2005), as can secure housing (Browne & Courtney, 2005a). Mindfulness techniques can be beneficial here too, helping patients find, in one participant's words, "that basically that I'm not wrong, that I'm quite acceptable" (Abba et al., 2008, p. 85). Meaningful activity, having a task which goes beyond simply having a job (Wagner & King, 2004), is also of central importance to regaining self-esteem (Yilmaz et al., 2009), with the form of such activities varying widely (Noiseux et al., 2008; Geanolos, 2005). Sub-Theme II: Rebuilding and reforging hope and fighting back Regaining hope is crucial (Koivisto et al., 2004), evidenced by statements such as "when... you're hearing voices... sometimes hope is the only thing you've got" (El-Mallakh, 2006, p. 61). Sources of hope include the support of family and friends (Wagner & King, 2004; Perry et al., 2007), friendships enduring with old friends (Schon et al., 2009), medication (Usher, 2001), positive attitudes from clinicians and confidence about recovery (Green et al., 2008),

being diagnosed (Dilks et al., 2010), the prospect of work or education (Usher, 2001; Perry et al., 2007; Liu et al., 2007), religion/spirituality (Humberstone, 2002; Drinnan & Lavender, 2006; McCann & Clark, 2004; Wagner & King, 2003), and understanding and/or meeting other people going through the same thing (Coffey et al., 2008; Powell et al., 2006; Newton et al., 2007; Schon et al., 2009). Patients hope for restoration of family relationships, close interpersonal relationships, employment, energy, health, spiritual fulfillment or just a 'normal' life (Chernomas et al., 2000; Koivisto et al., 2004; Gould, 2005; Noh et al., 2000). Whilst recovery may be conceived by patients as involving no need for medication, clinicians may see recovery as being possible only whilst taking medication (Ng et al., 2008). Maintaining hope is hard work (Woodside et al., 2006; Geanollos, 2005; Tooth et al., 2003), with the idea of a daily fight appearing (Noiseux et al., 2008; Shea et al., 2010; Volman, 2007); "You just gotta fight. You can't give up" (Shea et al., 2010, p. 47). Sub-Theme III: Rebuilding and reforging security in body and world The body must be re-secured. Sleep, aided by medication, for example, is helpful: "Medication is calming and I am a lot more relaxed. I have slept easier" (Rofail et al., p. 1491). In some studies, participants also reported cannabis helped with sleep (Costain et al., 2008; Wagstaff et al., 2007).<sup>2</sup> Regaining a sense of peaceful safety in the world is also central to recovery (Campbell & Morrison, 2007), both on wards (Koivisto et al., 2004) and at home (Ma et al., 2005; O'Toole et al., 2004). Secure housing is of great importance; "I can't do nothing til I've got somewhere" (Hardy et al., 2009, p.55). Many return to live with parents, due to a supportive atmosphere freeing up their resources to deal with other challenges (Woodside et al., 2008). Many also want to return to the security of work (Dilks et al., 2010; Gioia, 2006; Marwaha et al., 2005) with financially security aiding physical security (Roe et

<sup>2</sup> Other studies found that such drug use made symptoms worse (Lobbanna et al., 2009).

al., 2004), yet they may be caught in a benefits trap (Marwaha et al., 2005; Gioia, 2006). Stigma is a key barrier to returning to work (Bassett et al., 2001; Marwaha et al., 2005; Schulze et al., 2003), as are psychotic experiences themselves (Gioia, 2006; Woodside et al., 2006), and side-effects of medication (Kennedy-Jones et al., 2005, Marwaha et al., 2005; Rofail et al., 2009; Woodside et al., 2006). Many worry that the pressures of work might lead to relapse (Dilks et al., 2010), and are aware of the need to monitor the amount of stress work is placing on them (Kennedy-Jones et al., 2005; Bassett et al., 2001; Marwaha et al., 2005; Chernomas et al., 2000). Yet, stress may also be found invigorating (Roe et al., 2004). To help with re-employment, many want programs to help them prepare for work (Bassett et al., 2001; Liu et al., 2007).

Sub-Theme IV: Rebuilding and reforging relationships, and recovering through them Humberstone (2002) noted that "Every participant spontaneously discussed their family and their desire to be closer to them" (p. 370). Whether relations brake down due to the actions of participants, or the actions of others, reconnecting with people is not easy (Mauritz et al., 2009; Schulze et al., 2003), due to factors such as medication side-effects, poor communication skills (Skodlar et al., 2008), and stigma (Diaz-Caneja et al., 2004), as well as the need to potentially mend fences (Krupa et al., 2010; McCann & Clark, 2004). The aid to recovery of a supportive network of friends, particularly friends with a sense of humour (Lencucha et al., 2008), and social relationships generally are frequently stressed (McCann & Clark, 2004; Schon et al., 2009). This can result in a lower probability of suicide (Skodlar et al., 2008), aid a return to work, in turn further aiding social relations (Kennedy-Jones et al., 2005; Gee et al., 2003; Perry et al., 2007; Woodside et al., 2006). The need to regain romantic relationships and to have a family is also important (Laliberte-Rudman et al., 2000; Wagner & King, 2004) and can make people feel 'normal' again (Redmond et al., 2010). Relationships with mental health professionals and hospital staff can also be instrumental to

recovery (Cook et al., 2009; Laithwaite et al., 2007; Nixon et al., 2010a). Being listened to, having continuity with a clinician (McGowan et al., 2000), and being "treated like a human being" (O'Toole et al., 2004, p. 321) by mental health professionals are cited as key to recovery.

Factors cited as helping regain social relations include religion (Drinnan & Lavender, 2006), routine (Lencucha et al., 2008) and medication (Rofail et al., 2009). Relations are easier when friends and family understand the participant's experiences (ibid), have a positive attitude towards their mental illness (Browne & Courtney, 2005b), do not judge them (Mackrell & Lavender, 2004; Tooth et al., 2003; Shea et al., 2010) and demonstrate constancy (Lencucha et al., 2008). Friendships with people who shared similar psychotic experiences (Nixon et al., 2010a) can help give a valued sense of solidarity (Knight et al., 2003; Lencucha et al., 2008; Pitt et al., 2009).

## Theme 4: Better than new: gifts from psychosis

A theme was found of participants not just restoring their old self and world, but building higher than before. Gifts may be gained from psychosis (Knight et al., 2003; Woodside et al., 2006), such as a reconnection with a sense of creativity and increased compassion for others, for example, by becoming advocates for other service-users (Robertson & Lyons, 2003; Nixon et al., 2010a); "I've seen reality, I've seen people suffering on that ward and it makes me value my life and to think how lucky I am" (p. 9). Improved family relationships can also be found (Gee et al., 2003). Yet, although participants may find their experiences beneficial in some way, relatives may not share this view (Barker et al., 2001).

#### Discussion

This is the first systematic meta-synthesis of the extant qualitative research on the experience of psychosis. Four themes associated with the experience of psychosis were generated.

'Losing' highlighted the loss of consensual reality and self, the fear and confusion this led to, and the intertwined losses of hope and basic human needs such as sleep, physical and financial security, relationships with friends and family, and self-esteem. The searing effects of stigma, negative interactions with the mental health system, and side-effects of medication contributed prominently to these losses. 'Identifying a need for, and seeking, help' highlighted the recognition of problems, factors impeding help-seeking, and the issues arising surrounding a move to a mental illness-based explanation of one's experiences. 'Regaining and reforging' found medication, sense-making (aided by peers), and detachment from experiences, could lead to the re-establishment of self and a less confusing and more meaningful reality. Participants sought to regain hope, work, financial stability, safe housing and to recover all forms of relationships, and to regain self-esteem and self-identity. This formed an essential part of recovery, and was undertaken in the face of pervasive stigma. Finally, 'Better than new: gifts from psychosis' observed that participants could take positives from their experience of psychosis, including greater compassion for others and increased creativity.

Our findings can be compared to the wider published literature in this field. First, the importance of hope is consistent with the focus on hope in contemporary recovery models (Repper & Perkins, 2003). Yet, our finding that hope was often lost or damaged by interactions with mental health professionals suggests more attention and care still needs to be paid to this. The centrality of regaining basic human needs, and the hope for a normal life, supports recovery models which argue services should be judged in terms of the degree they allow people to live the life they wish to life rather than being assessed by solely 'psychotic symptom reduction' (ibid). Nevertheless, the criticisms that have been leveled against recovery models (Davidson et al., 2007) highlight the practical difficulties with the concrete implementation of such proposals.

Second, a number of our sub-themes highlighted the importance of social relationships and the pain of loneliness in psychosis. This suggests that intervening with social/relationship issues at an early stage, could be an important clinical task. Third, our meta-synthesis supports arguments that recovery is a process that involves professionals, users, and carers talking and listening to each other (Coleman, 1999). Indeed, in line with Coleman's (1999) argument that "economic independence is a myth for many clients as is residential independence" (p. 38), we found an important need to regain a secure financial and employment situation, as well as secure housing, but a lack of studies clearly documenting how this was to be achieved. More work hence needs to be done on stigma reduction, and delineating clear pathways to financial and residential security for those attempting recovery. In order to achieve the former aim, it may be valuable to consider which of the specific functions of stigma proposed by Phelan et al. (2008) public attitudes/behavior are serving (exploitation and domination, disease avoidance, or norm enforcement), as well as what specific problems stigma arises from (Thornicroft et al., 2007).

The quality of the qualitative studies employed varied widely. One key limitation of the many papers included in our review was a lack of respondent validation, and the failure to employ service-users on a consultative basis, as co-researchers, or as commissioners. Ironically, given the number of studies that examined themes of respect, this could be interpreted as another way in which service-users views were marginalized. Furthermore, some of the studies utilized did not use a recognized framework for their thematic analysis, which may pose a threat to one's faith in the rigor of the analytical processes undertaken. Nevertheless, although the trustworthiness of the studies reviewed varied, they all included sufficient information to satisfy us that the themes extracted were grounded in participants' accounts.

Our meta-synthesis itself had a number of limitations. Firstly, the majority of studies employed in this study were from Western European and North American cultures. This limits the cross-cultural generalizability of our results. Secondly, we only considered papers published over the last decade, and hence may have excluded other relevant studies, including those written by service users, that are more likely to be contained in the grey literature (papers and reports not distributed or indexed by commercial publishers) and might have contained further important themes. The limitation of our study to the use of inductive studies also led to the exclusion of a number of other important qualitative methodologies such as discourse analysis.

In conclusion, our findings suggest that the mental health professionals seeking to share in or develop an understanding of the lived experience of those who they seek to help should be constantly aware of its broad impact on all areas of life and its multi-faceted nature. The potential for clinicians to have a destructive, as well as constructive impact on those with psychosis should also be at the fore of a reflexive approach to treatment.

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<sup>&</sup>lt;sup>3</sup> \*Included in the meta-synthesis.

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