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Doctoral Thesis

**The Relationships between Mental Health Experiences, Trauma
and Posttraumatic Growth**

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Thesis Section	Text	Appendices (incl. references and tables)	Total
Abstract	280	-	280
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The Relationships between Mental Health Experiences, Trauma and Posttraumatic Growth

This doctoral thesis explores the relationships between distressing mental health experiences and the interventions people may receive for these experiences, and trauma. It then looks at whether this trauma can lead to posttraumatic growth (PTG). It includes a narrative literature review, a research paper, a critical appraisal, and an ethics section.

The narrative literature review aimed to explore what elements of mental health inpatient support could be considered to be traumatic. A framework was developed which incorporated current understandings of trauma, and which was then used to interrogate qualitative studies investigating experiences of inpatient care. The review showed that throughout the process of hospitalisation, from being admitted, to being on the ward, to the experiences following discharge, people endure a wide range of experiences that could be considered to be traumatic, and will often undergo multiple experiences, thus compounding the trauma. Recommendations for clinical practice are discussed in relation to the findings.

The research paper aimed to learn if the PTG some people experienced soon after experiencing psychosis remained with them over time. Narrative analysis was used to unpack participants' stories of psychosis that they felt led to positive change. There was a clear structure of the stages that individuals moved through; Preface – A Time of Difference; Chapter 1 – The Crisis: Lost Connections; Chapter 2 – Acceptance and Connections; Chapter 3 – Life Now has Transformed; and the Epilogue – Looking Forward. The characters that supported individuals to reach PTG were also apparent. Clinical implications for working with psychosis are discussed, along with recommendations for future research.

The critical appraisal presented my personal and professional journey of understanding psychosis, and how this research has introduced me to new and different ways of thinking.

Declaration

This thesis records research undertaken for the Doctorate in Clinical Psychology Course at the Division of Health Research at Lancaster University, from May 2015 to June 2016. The work presented here is the author's own except where due reference is made. The work has not been submitted for the award of any higher degree elsewhere.

Natasha Goakes

Signed:

Date: 31st August 2016

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Section One: Literature Review

Are mental health inpatient experiences traumatic? A narrative review

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Abstract

Research has shown that although mental health inpatient care can provide support for some individuals, it can also be distressing or even traumatic for others, in some cases leading to experiences such as posttraumatic stress disorder. There are no qualitative studies investigating the traumatic aspects of inpatient care, however, there are studies investigating the experience of inpatient care. This narrative literature review interrogated these studies in an attempt to explore what elements of mental health inpatient support could be considered to be traumatic. A framework was developed which incorporated current understandings of trauma, and which was then used to interrogate the studies. The review showed that throughout the process of hospitalisation, from being admitted, to being on the ward, to the experiences following discharge, people endure a wide range of experiences that could be considered to be traumatic, and will often undergo multiple experiences, thus compounding the trauma. Recommendations for clinical practice are discussed in relation to the findings

Key words: *narrative literature review, inpatient, experiences, trauma*

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Are mental health inpatient experiences traumatic? A narrative review

Around the world, mental health inpatient wards are used to as safe, secure places for people experiencing a mental health crisis (World Health Organisation [WHO], 2003). Although this is their aim, not everyone experiences them this way, and may in fact experience inpatient care as traumatic (Morrison, Bowe, Larkin & Northard, 1999). It is therefore important to establish which aspects of inpatient care can be considered traumatic. The history and purpose of mental health inpatient wards is described below, and is followed by a framework for understanding trauma that was developed to ensure clarity over how trauma is understood in this review. This framework was used to interrogate studies investigating experiences of inpatient care. A narrative format was chosen for this review, as it allows a broad coverage of evidence, and is flexible enough to allow controversial concepts to be explored in depth (Collins & Fauser, 2005). A narrative approach also allows a focus on context and the use of evidence to support the developing argument (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005). Within this format, a systematic approach to the search was taken in an effort to be as thorough and inclusive as possible. The details of the search are included to ensure transparency and strengthen the review (Collins & Fauser, 2005).

Until the 18th Century, across many Western countries, those experiencing mental distress were primarily cared for by family or religious orders (Shorter, 1998). By the early 1900s, this care shifted to large, purpose built state asylums (Wright, 1997). Although initially designed around the premise of “moral treatment” developed in the Quaker hospital, the York Retreat, these institutions grew large and overcrowded, and the ideals of moral treatment were lost (Borthwick et al., 2001). Doctors ran some (although not all) of these asylums, and medicine and biology became the lenses through which mental distress was understood and treated (Bynum, Porter & Shepherd, 2004).

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This medical model has traditionally been seen to focus on a biological understanding of mental distress, and to relate the concept of recovery to being symptom free (Slade, 2009). An alternative understanding of recovery arose from the publishing of service users' stories of recovery (Slade, 2009). This "recovery approach" emphasises people's personal understanding of recovery (National Institute for Mental Health in England (NIMHE), 2005). Many countries began adopting this approach in the early 2000s, including New Zealand (O'Hagan, 2004), United States (New Freedom Commission on Mental Health, 2003), Australia (Rickwood, 2004) and the United Kingdom (UK) (NIMHE, 2005), and aim to use the principles in inpatient and community care. Services using this approach ensure they provide meaningful activities that promote recovery, and also ensure that staff offer hope to service users, promoting an individualised approach to mental health care (Stickley & Wright, 2011).

Over the last 50 years, there has been a focus on deinstitutionalisation and a return to community support in many countries including the UK (Quirk & Lelliot, 2001), Australia (Doessel, 2009), United States, Western Europe and in Scandinavia (Novella, 2010). The principle guiding the use of inpatient care since deinstitutionalisation is that people should only be admitted to inpatient wards if they need support that cannot be provided by community mental health services (WHO, 2003). However, despite this principle of least restrictive care, data suggests that internationally, although involuntary admissions decreased immediately following deinstitutionalisation, they subsequently increased (Novella, 2010).

If people agree to go into hospital, they are admitted to an inpatient ward voluntarily (Royal College of Psychiatrists [RCP], 2013). Alternatively, an individual may not want to go into hospital, but the state may deem they should be admitted involuntarily. WHO (2003) have created a guidance package for countries to use when developing legislation around admitting an individual against their will. Research has shown that in the UK, the majority of

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admissions tend to be unplanned emergencies with people entering wards involuntarily (Quirk & Lelliot, 2001), or that people are detained once on the ward, meaning the majority of people on a mental health ward are under detention (Health and Social Care Information Centre, 2014).

It is important to note that this review is not discounting the potential positive effect that mental health inpatient wards can have, for instance, some people view the ward as a place of safety and shelter (Katsakou & Priebe, 2007). Staff are often viewed positively, with service users feeling they are available to talk to, and have confidence in their ability to recover (Howard, El-Mallakh, Rayens, & Clark, 2003). People often appreciate feeling cared for (Katsakou & Priebe, 2007).

However, there is research showing that people can find inpatient wards distressing or traumatic. For instance, people dislike having their autonomy restricted (Katsakou & Priebe, 2007), and may experience practices such as restraint as traumatic (Frueh et al., 2005). Furthermore, research has shown that some people on inpatient wards have experienced physical or sexual assault, or have witnessed traumatic events whilst in hospital (Frueh et al., 2005).

Research has looked into whether inpatient support can lead to posttraumatic stress disorder (PTSD). For instance, Morrison et al. (1999) carried out a survey with people who had experiences of hospitalisation, and found that 44% of those who took part experienced PTSD. However, this quantitative study involved postal questionnaires, and did not further explore what elements of hospitalisation were traumatic, or people's understanding of their experiences. This review therefore is looking at qualitative papers to investigate the experience of inpatient wards, in the hope of learning what elements of the experiences are considered traumatic.

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A framework for understanding trauma

In order to make sense of the ways in which inpatient experiences can be experienced as traumatic for some people, it is important to establish a clear framework for understanding what we mean by trauma. This framework was developed following the reading of literature around trauma. Key elements which appeared to differentiate traumatic experiences from distressing ones, for example, powerlessness, were noted, along with the ways those elements were understood by various authors. These elements were then combined into the following framework.

One way of understanding trauma is through the use of pre-existing definitions that are used for diagnoses such as PTSD. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), for instance, has established a narrow definition, whereby an event is traumatic if it consists of “exposure to actual or threatened death, serious injury or sexual violation”, and that the event can be considered traumatic whether a person experiences it themselves, or witnesses another person experience it (American Psychiatric Association, 2013, p. 274).

This definition has changed throughout editions of the DSM and has prompted controversy and criticism (Rosen & Lilienfeld, 2008). One criticism of this definition is that unlike previous definitions, it fails to acknowledge any *subjective* element to trauma, meaning the same events will be traumatic for anyone who experiences them, regardless of their interpretation of them. Additionally, trauma is limited to the threat of “death” or “serious injury”, which discounts experiences that many would consider to be traumatic, but which would not result in death or serious injury. Furthermore, studies have demonstrated that people can experience PTSD from events that do not fit within the DSM definition of traumatic, for example, divorce, money problems, or dental surgery (Dreman, 1991, Scott & Stradling, 1994, de Jongh et al., 2008). Additionally, as stated above, the definition has not

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remained consistent, and has changed with each edition of the DSM; for instance, DSM IV included a more subjective element, by stating that for an event to be traumatic, the person must experience fear, helplessness or horror following the event. Despite the fact that some research has suggested that this subjective element is able to predict the magnitude of the resulting reaction to trauma (Creamer, McFarlane & Burgess, 2005), it was removed from the current manual.

The diagnostic manual in use in the UK, the International Classification of Diseases (ICD), also has a definition of trauma with regards to the diagnosis of PTSD; a situation is traumatic if it has “an exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone” (WHO, 1990, p. 120). This definition appears to be somewhat broader than that in the DSM, as it does not specify that a traumatic event must entail threat of death or serious injury. However, although it appears to acknowledge the potential subjectivity of trauma, there is the point that for an event to be considered traumatic, it must be considered to be so by “almost anyone”. This raises the question of whether Person A’s interpretation of an event as traumatic is valid, if Persons B-Z would not consider it to be so.

The key point here relates to how we understand people’s experiences. The DSM and the ICD are coming from a realist perspective (Lovett & Hood, 2011). As diagnostic manuals they are underpinned by a belief that reality is concrete and measurable, and we can quantify and categorise it. Therefore, in this perspective, “trauma” is something that is definable and measurable. Events that do not fit within that definition are quite simply, not traumatic.

However, an alternative perspective in mental health, is that people, and their experiences, are not as simple as this (Harper & Spellman, 2006). It can be argued that psychological events could be considered to be the product of an interaction between internal

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processes belonging to an individual, and external social structures (Archer, 1995). This paper is coming from a critical realist perspective, acknowledging that although reality exists separately from our knowledge of it, it can only ever be understood through our “perceptual filters” (Frauley & Pearce, 2007, p. 4). Therefore, our understanding of reality is used to make sense of our experience of it, and can be adjusted and revised as our experiences change (Frauley & Pearce, 2007).

If we recognise the personal meaning making involved in understanding an experience, the framework for understanding trauma becomes much broader. For instance, Allen highlights the difference between events themselves, and how those events are experienced; “*the subjective experience of the objective events constitutes the trauma*” (2005, p. 21). Thus it is the interaction between the external event and the person’s internal processing of it that constitutes the trauma, and as a result could be different for each individual. This allows for an event to be traumatic for one person, and not for another, as Allen highlights that there is not always a match between an objective event and the subjective experience (Allen, 2005). This means that an event that many would consider to be traumatic may not have been for that individual, and vice versa.

If we acknowledge the subjective aspect of trauma, this raises the question of what it *feels like* to experience the trauma. Allen proposes that a trauma evokes “overwhelming emotion” and feelings of “utter helplessness” (2005, p. 22). Similarly, McFarlane and de Girolamo highlight that key aspects of a traumatic experience are feelings of helplessness and powerlessness (1996). It is perhaps unsurprising that key elements of trauma include feelings of helplessness, fear and powerlessness. These feelings challenge our natural assumptions of ourselves as in control of our own lives (van der Kolk & McFarlane, 1996), and we learn that we can be randomly subjected to physical or psychological pain.

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In keeping with the idea that a trauma challenges our understanding of the world, Janoff-Bulman described three core assumptions that most people have; the world is benevolent, the world is meaningful, and the self is worthy (1992). She suggests that a trauma is an event that shatters these core assumptions. Events that are likely to shatter these assumptions are ones that are “out of the ordinary and are directly experienced as threats to survival and self-preservation” (1992, p. 53). A threat to survival does not just include an explicit threat of death; it is essentially anything that reminds us of our vulnerability in the world, stripping us of our belief in ourselves as autonomous, capable beings in charge of our own lives, instead rendering us essentially powerless.

In keeping with the idea that trauma causes feelings of powerlessness and helplessness, Briere and Scott identify that a traumatic event “temporarily overwhelms the individual’s internal resources” (2015, p. 10). These internal resources are key aspects of a person’s identity and sense of self (McFarlane & de Girolamo, 1996). When these become violated, or “overwhelmed”, we lose our ability to make sense of the world and ourselves in it. Our way of interacting with the world becomes invalid and useless. Once again it is apparent that an individual’s internal processes shape their experience of an external event as traumatic or not. Similarly, Pearlman and Saakvitne highlight that we must focus on people’s own understanding of events, and describe trauma as an event which “overwhelms the individual’s ability to integrate affective experience” (1995, p. 60).

Calhoun and Tedeschi suggest that events are traumatic if they are “perceived as undesirable and uncontrollable” and “threatening to one’s life and general well-being” (1998/2008, p. 216). Once again, it is the way that an event is perceived and understood that influences how traumatic it is. Alongside threat to life, Calhoun and Tedeschi include threat to general well-being, which presumably includes psychological and emotional well-being as well as physical.

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For further elements of what constitutes a traumatic event, we could consider the traumagenic model of child sexual abuse developed by Finkelhor and Browne (1985). They highlighted four key aspects which can be considered traumatising; traumatic sexualisation, betrayal, powerlessness and stigmatisation. Although these four elements occur together in child sexual abuse, they can occur (individually or combined) in other types of trauma (Finkelhor & Browne, 1985).

Another important aspect to bear in mind when considering what constitutes a traumatic event is the distinction between impersonal trauma, such as natural disasters, interpersonal trauma, such as assault, or attachment trauma, for instance, child abuse (Allen, 2005). The difference between interpersonal and attachment trauma is that interpersonal trauma tends to involve actions from others to whom there is no emotional attachment. Attachment trauma, however, as the name suggests is trauma which occurs in relationships “where there is a close emotional bond and a high degree of dependency” (Allen, 2005, p. 7).

A further consideration in the interplay between trauma and attachment is that a secure early attachment can help reduce the impact of trauma, both in childhood (Busch & Lieberman, 2007), and adulthood (Berry, Danquah & Wallin, 2014). This is understandable when we consider that the purpose of attachment is to enable a person to feel secure in the world (Bowlby, 1988). This fits with Janoff-Bulman’s theory of shattered assumptions. The assumptions that the world is benevolent, the world is meaningful, and the self is worthy are likely to stem from our early interactions with sensitive caregivers (1992). These assumptions will be well-established for an adult, therefore following a trauma, they may be able to rebuild these assumptions, because they have the psychological resources available to do so. A child’s assumptions, however, are likely to be more malleable, and early abuse may become incorporated into their understanding of themselves and the world, and go with them into adulthood (Janoff-Bulman, 1992). It is therefore understandable that adults with a

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history of childhood abuse may be more negatively impacted by trauma than those with a history of secure attachment (van der Kolk, 1996).

Lenore Terr (1991) makes the distinction between single blow and repeated trauma, highlighting that often repeated trauma results in more difficult experiences later in life. Similarly, van der Kolk and McFarlane (1996), among others, have highlighted that often people who have experienced a traumatic event, will go on to experience further ones, for instance, adults who are sexually assaulted may well have been abused as children highlighting how trauma can be compounded in people.

Finally, it is important to consider the aftermath of trauma, such as the emotional responses to trauma. Allen (2005) highlights that following a trauma, people can experience “cynicism, bitterness, distrust, alienation, hatred, vengefulness, demoralisation, loss of faith and loss of hope” (p. 5). This intense mix of emotions become understandable when we consider that for those who have experienced a trauma, the external world becomes a dangerous, frightening place, and they cannot trust their own assumptions to guide them through it, as their internal world is also in chaos (Janoff-Bulman, 1992).

To summarise, there appear to be various elements that can come together to constitute a trauma. The most important aspect to hold in mind when deciding if an event is traumatic is the individual’s personal understanding of the event. Another key element of traumatic events is that they engender a feeling of powerlessness in the individual. Their preconceived assumptions about themselves as invincible or in control of their own lives are destroyed, and alongside this comes the destruction of the assumptions of the world and others as benevolent. Following trauma, a person is aware of their own vulnerability in a dangerous world, peopled with others who may have malevolent intent, and may experience a mix of emotions such as bitterness and demoralisation, or a loss of hope, trust and faith. It is also important to bear in mind previous trauma, and the impact of repeated trauma.

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Alongside this, the impact of attachment needs to be taken into account, both early attachment, and the current relationship a person has with the other who has caused the trauma. Finally, trauma may also include aspects of uncontrollability and suddenness, threats to well-being, and feelings of betrayal and stigmatisation, all of which combine to render the individual temporarily overwhelmed.

Method

The best way to understand people's subjective experiences is through qualitative research (Chambers, 1998), so this review focused on qualitative studies. As there are no qualitative studies looking specifically at traumatic experiences of hospitalisation, the review investigated studies describing people's experiences as a whole. The author used the framework outlined above to develop a secondary level of interpretation of these findings, to learn what elements of inpatient experience constitute trauma. Where possible, original quotes from participants are included to highlight traumatic elements, in an effort to remain true to participants' voices (Avis, 1997). An audit trail is described below in an effort to enable transparency, however, it should be acknowledged that the interpretations rely on the author's reading of the papers selected.

Search Strategy

A search for relevant papers was conducted on databases MEDLINE and PsycINFO, using the search terms (mental health services OR psychiatric OR inpatient) AND (patient OR service user OR consumer) AND experience AND (informal OR formal OR voluntary OR involuntary). The search was conducted on 31/10/15, and papers published on or before this date were included. As the recovery approach was beginning to be adopted around the early 2000s, studies published before 2000 were excluded as they would not be indicative of current inpatient experiences.

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The total returned number of papers was 1207, 318 of which were duplicates. After reading the title and/or abstract, 870 studies were excluded, leaving 20 which appeared suitable. These were read in full and a further seven were excluded as they did not meet the inclusion or exclusion criteria. A further two studies were identified following hand-searching of reference lists, resulting in a total of 15 studies being included in the study. Details of the studies are included in Appendix 1-A.

Selection Criteria

Studies were included if:

1. They focused on service user experience of hospitalisation.
2. They used a qualitative method.
3. They were published in peer-reviewed journals (to ensure quality of studies).
4. They were in English.

Studies were excluded if:

1. They focused on secure services, or drug/alcohol services.
2. They included views of staff or family members which were not distinguishable from those of service users.
3. They were published prior to 2000.

The author undertook repeated readings of the studies to familiarise herself with the data.

She then used the main elements of traumatic experiences from the above framework to note the quotes in each study that appeared to fit one or more of these elements (see Appendix 1-B). From the quotes it was apparent that the elements of traumatic experiences interacted in different ways in each experience, and that the experiences occurred throughout hospitalisation; admission to hospital, spending time on the ward, and the aftermath of hospitalisation.

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Going into Hospital

For many people, admission to a mental health inpatient unit was experienced as sudden and unexpected, for example, a physician abruptly stating “Well now you will be admitted to involuntary care” (Johansson & Lundman, 2002, p. 643). This suddenness demonstrates how a person might feel powerless during admission (McFarlane & di Girolamo 1996). Furthermore, those who went into hospital involuntarily felt as if their opinions were not respected during admission (Olofsson & Jacobsson, 2001). This lack of respect appears to be felt by some people throughout hospitalisation, and can, at its extremes, be experienced as being treated as less than human (discussed below).

Alongside admission feeling sudden and unexpected, it can engender feelings that events have spiralled out of a person’s control (van der Kolk & McFarlane, 1996). As highlighted by Gilbert, Rose and Slade (2008), participants felt that even when they “voluntarily” went into hospital, this was actually an imposed decision; “My GP at the time said either you go in or I section you” (p. 4). This raises questions about how clinical decisions around admission are made, and explained to the person. As highlighted earlier, the decision to detain an individual is not one that should be taken lightly, however, it should not be avoided by coercing them into going into hospital under threat of detention. Unfortunately, coercion in the mental health system is a long running concern (Laurance, 2003).

One participant in the study by Katsakou et al. (2011) commented “it certainly didn’t feel like I had a choice, so I got angry” (p. 278), illuminating a key issue with experiences of coercion; individuals being told they have to be somewhere against their will is likely to cause anger, and aggression, possibly stemming from attempts to regain control of their lives (van der Kolk & McFarlane 1996). Unfortunately, the aggression may very well reinforce

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clinicians' decisions around how "risky" a person is and appear to confirm a decision to admit.

Furthermore, admission can feel out of control when people are "taken away", for instance, by the police. One person in Katsakou et al.'s (2012) study shared their realisation; "After being sectioned I've realised that police can walk in at any time in your own home! It's MY home! ... and drag me out in handcuffs" (p. 1178). A similar sense of violation is apparent in the study by Olofsson & Jacobsson, (2001). Similarly, one participant in the study by Fenton et al. (2014) described being taken away in the back of a police van with little understanding of why; "I just thought, 'I'm gonna die'" (p. 236).

Being taken from your home by police officers is likely to impact on your assumptions about your self-worth (Janoff-Bulman, 1992), and lead to negative judgement or stigmatisation from neighbours; "Children in the street are stoning my windows! I've been labelled by being dragged out by the police" (Katsakou et al., 2012, p. 1178). This quote highlights the possibility that the stigma that stemmed from the intervention of the police may be over and above stigma traditionally experienced for having a mental illness (Wahl, 1999). Alternatively, the stigma may stem from the mental illness becoming apparent to others, due to being taken to hospital by police. As highlighted by Finkelhor and Browne (1985), stigma can be a key element that leads to an event being experienced as traumatic. This stigma may become internalised and experienced as shame (Katsakou et al., 2012), further impacting on an individual's assumptions about themselves (Janoff-Bulman, 1992).

In addition, people being considered for mental health admission are likely to be in a confused state of mind, feeling "terribly fragile" (Andreasson & Skärsäter, 2012, p. 18), and these experiences of coercion or detention may be experienced as a betrayal by professionals. As highlighted by Finkelhor and Browne (1985), feelings of betrayal may lead to an event to be experienced as traumatic. For instance, in the above quote from Gilbert et al. (2008), it

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was the participant's GP who issued that ultimatum, a GP they presumably turned to for help. Although it can be argued that the GP is helping in the best way they can in an imperfect system, this response may still feel like a betrayal, especially if the individual is trying to acknowledge their difficulties; "In a way I wanted to face up to my problems... but I felt really intimidated, pressured into going" (Katsakou et al., 2011, p. 279).

From the above, it is apparent that people often experience being detained as sudden and confusing. In the UK, when detained, a person should have their rights explained to them on arrival at the hospital, be given a copy of these rights, and be offered the services of an independent mental health advocate (RCP, 2013). However, as discussed earlier, people who are detained are likely to be feeling highly anxious and agitated, or extremely low in mood. Research into how we process information shows that anxiety has an adverse impact on people's attention and memory (Derakshan & Eysenck, 2009). It is therefore possible that in the incidents described above, those participants were given the required information, but they did not assimilate this information, highlighting the possibility that the experience of admission had overwhelmed their internal resources and processing ability (Briere & Scott, 2015).

Additionally, when people are experiencing a mental health crisis, it is possible their understanding of reality may be affected. As discussed above, a person's understanding of a situation is relevant when considering if that situation is traumatic. This was demonstrated clearly in Gregory and Thompson (2013), when Alex (writing in an autoethnographic article) described being taken to a place of safety while experiencing fears that her family and the police were planning to harm her; "My fear was palpable. I thought, 'now they [the police] are going to kill me and put me in that skip'" (p. 461). This quote shows how even being taken to a place of safety could be a traumatic experience, especially if the individual is unsure of the intentions of those taking them, and also demonstrates the way in which an

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objective event and the subjective understanding of the event may not correspond (Allen, 2005). This subjective understanding of being in danger is likely to cause feelings of fear, and may lead to aggression, for instance defending the self, in a similar way that feeling coerced might (Johansson & Lundman, 2002).

While on the Ward

Following admission, people may continue to experience situations that result in them feeling powerless, such as restraint; “When I came here they put me straight into those resting bonds and they didn’t tell me what was happening”, (Koivisto, Janhonen, & Väisänen, 2004, p. 272). In this example, it is possible that the combination of a lack of knowledge and understanding and the inability to move may engender feelings of “utter helplessness” as described by Allen (2005, p. 22). Furthermore, the way in which restraint occurs could lead to it being experienced as traumatic; “I wasn’t restrained, I was attacked” (Gilburt et al., 2008, p. 4). This appears more likely when restraint is used to administer compulsory medication; “drag you to the bed and give you the injection with force and a lot of people are holding you” (Johansson & Lundman, 2002, p. 643). These experiences may leave an individual feeling powerless and helpless (McFarlane & di Girolamo 1996), and also shatter their assumptions of others as benevolent (Janoff-Bulman, 1992).

Experiences of restraint and compulsory medication may also feel like a continuing betrayal of trust (Andreasson & Skärsäter, 2012; Olofsson & Jacobsson, 2001), or a punishment (Hughes, Hayward & Finlay, 2009; Mayers, Keet, Winkler, & Flisher, 2010), possibly shattering an individual’s assumptions of themselves as worthy of care and affection (Janoff-Bulman, 1992). It is important to note that these experiences of betrayal and punishment may echo an individual’s early life experiences, and may be repeating negative or traumatic childhood experiences (Steele & van der Hart, 2014).

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Typically, restraint is used by ward staff when a patient is highly agitated, and, as discussed above, when in this state, an individual's ability to process information is likely to be impaired (Derakshan & Eysenck, 2009). It is therefore understandable that a patient may not realise why they are being restrained, and may come up with their own explanation for what is happening to them; fearing they are near death; "I thought I would die" (Koivisto et al., 2004, p. 272); "They injected me and I thought I was going to die" (Katsakou et al., 2012, p. 1173). Or they may believe an alternative, highly traumatic event is happening:

They took me back to the room, they put me face down on the bed, actually holding my face into the cushions, so that I couldn't breathe. I was fighting and fighting. And they were saying, um, go on, pull her trousers down and stick it in her arse. I thought they were raping me (Hughes et al., 2009, p.157).

These interpretations may be due to re-experiencing of past traumas, as are likely to cause many similar feelings. As highlighted by Creamer et al. (2005), the subjective understanding and emotions that arise during an experience can predict the magnitude of the reaction to it, therefore, it is possible that these intense thoughts and feelings will ultimately have a negative impact on those who experienced them.

It is also important to consider non-emergency prescribed medication, which can have very unpleasant side effects such as muscle stiffness, or involuntary movements of the mouth, jaw and tongue caused by antipsychotics (RCP, 2014). Often people are prescribed medication despite not wanting it, leading to feelings of powerlessness in relation to others, "I get different injections and I try to explain that they are giving me too many, but I get dismissed and they don't listen. It makes me feel upset and like a guinea pig" (Wyder, Bland, Blythe, Matarasso & Crompton, 2015, p. 185). In this description, it is apparent that the individual felt they had lost control over their own life (van der Kolk & McFarlane, 1996). Feelings of powerlessness may also arise from the side effects, leaving a person feeling as if

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their body is no longer under their control; “I couldn’t talk, my mouth was locking, my mouth was like twisting, it really hurt [...] And I couldn’t talk to let them know what was wrong” (Hughes et al., 2009, p. 157). In this instance, medication has become a threat to physical wellbeing (Calhoun & Tedeschi, 1998/2008).

Being prescribed medication despite not wanting it can also lead to feelings of betrayal; “I said in my Advance Statement I didn’t want C or D and they piled on the full dose” (Ridley & Hunter, 2013, p. 514); “I used to plead with them and plead with them (tearful), please don’t give me that [medication]” (Hughes et al., 2009, p. 157). It is apparent that these feelings of betrayal are linked to feelings of powerlessness and helplessness (McFarlane & diGirolamo, 1996), and demonstrates that even medication not given under restraint can be experienced as traumatic.

These feelings of betrayal are understandable when we consider the importance of relationships between staff and service users on an inpatient unit (Sibitz et al., 2011), and the strong attachment feelings people might develop with staff; “you were in such a subordinate position, when you encountered love, it felt like you had made a friend” (Andreasson & Skärsäter, 2012, p. 19). Experiencing these strong positive relationships may reinforce assumptions of others as good and caring (Janoff-Bulman, 1992). However, due to the potential intensity of these relationships, it is likely that when the same staff become involved in restraint or sedation, this assumption of others as benevolent may be shattered; “they wanted to tear me to pieces and I have arthritis of the shoulder to prove it” (Gilbert et al., 2008, p. 4). This experience may be all the more powerful for service users who have a history of traumatic relationships with caregivers, and who now experience positive relationships for the first time (Goodwin, Holmes, Cochrane & Mason, 2003).

Alongside feelings of powerlessness in relation to staff, participants experienced these feelings in relation to other patients, for instance anxiety about other service users being

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nearby; “(...) it feels they are coming for you” (Fenton et al., 2014, p. 27). This can sometimes be the case, and can sometimes come with a warning; “I swear on Saint Christopher that I’ll fucking hurt someone” (Quirk, Lelliott & Seale, 2004, p. 2579), but sometimes can just happen (Gilburt et al., 2008). For some, there may be no actual act of violence, or threat, but they may feel afraid of other patients, simply due to the environment; “I continued to feel afraid of the young men who seemed to be prowling the wards” (Gregory & Thompson, 2013, p. 466). This illustrates that on an inpatient ward, people can experience threats to physical wellbeing (Calhoun & Tedeschi, 1998/2008), and also that these types of incidents may happen more than once, thus compounding the trauma (Terr, 1991).

Experiencing others as dangerous while unable to defend yourself could shatter assumptions of yourself as capable and able to influence the outcome of events (Janoff-Bulman, 1992). When fearful of violence from other patients, service users sometimes recruit staff to monitor the situation; “I’ve warned (a nurse) just in case” (Quirk et al., 2004, p. 2581). Although this strategy may work sometimes, on this occasion, it is reported that the service user was eventually assaulted by the other person described, in all likelihood thereby shattering her assumptions of herself as capable and in control, as she tried and failed to protect herself (Janoff-Bulman, 1992).

Furthermore, it is possible that simply being on a ward environment may shatter assumptions. Janoff-Bulman (1992) argues that we view the world as benevolent, despite all the evidence to the contrary, because we focus on our immediate environment. Thus if we are taken from that environment and placed in a new one; “I was put into what felt like a ‘padded cell’” (Gregory & Thompson, 2013, p. 464), our assumptions about the world as a safe, benevolent place may well be shattered, therefore it is understandable that being placed in this environment may be experienced as traumatic.

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A poor environment may also lead to some service users feeling as if they are less than human, or being treated as such; “It’s disgusting and I wouldn’t put a pig in there let alone a human being” (Gilburt et al., 2008, p. 8). These feelings may also stem from feeling as if they are little more than a label or a diagnosis; “Many staff members treat you like a case or number” (Wyder, Bland, Blythe et al., 2015, p. 184). Unfortunately, it also appears that simply being in hospital is sufficient to leave service users feeling as if they are less than human (Johansson & Lundman, 2002; Katsakou et al., 2011); “if you treat me like an animal, then I’ll act like an animal” (Hughes et al., 2009, p. 157). These examples also demonstrate how assumptions of the self as worthy can be shattered by being in hospital (Janoff-Bulman, 1992).

The last quote also illustrates how feeling as if staff are treating them as somehow less than human can lead service users to behave in a particular way, potentially resulting in cycles of aggression. Previous research has shown that people often feel powerless just before an aggressive incident, which itself leads to a feeling of power, albeit short-lived (Johnson, Martin, Guha & Montgomery, 1997). Service users may become aggressive, feeling they need to defend themselves in some way (Gilburt et al., 2008; Johansson & Lundman, 2002). Even if people do not resort to physical aggression, being treated in such a way may result in them becoming frustrated with staff, or ignoring advice; “It is the ‘high almighty’ that gets my back up and I switch off and I don’t listen any more” (Wyder, Bland, Blythe et al., 2015, p. 185). Despite attempting to regain power, it is likely that individuals may still be treated in the way they are trying to avoid, thus reinforcing a loss of control over their own lives (van der Kolk & McFarlane, 1996), and further impacting on their sense of selves as capable and worthy (Janoff-Bulman, 1992).

All the experiences described above may be repeated various times in various combinations, resulting in service users experiencing multiple blows of trauma (Terr, 1991)

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throughout their stay in hospital. Additionally, the feelings of high agitation experienced by service users on the ward will likely increase each time they undergo one of these traumatic experiences:

That used to make me more crazy, because I didn't know where to turn, I didn't know what to do (crying) [...] the more bad I was, the more I knew I was going to be medicated, so the more crazy I got, because I was terrified" (Hughes et al., 2009, p. 157).

It is also important to remember that many people going into mental health inpatient wards are likely to be experiencing poor mental health due to difficult or traumatic early experiences (Steele & van der Hart, 2014). As such, experiencing trauma in hospital may compound this past trauma by returning them to those past feelings of helplessness, powerlessness and terror; "I knew I was evil before I went into hospital, because of what happened in my childhood. [...] but, they, [...] exemplified it" (Hughes et al., 2009, p. 155). Additionally, people may be currently experiencing trauma or violence; "lots of people come from abusive and violent situations and the last thing they want is violence" (Quirk et al., 2004, p. 2577).

Aftermath of Hospital

Following hospital, some people may find that their experiences on the ward impact negatively on self-respect and identity; "I had no self-respect when I left there whatsoever"; "you are laid flat, like you are dead or something. And then you are gradually [...] built up [...] But you don't have any relationship with yourself, you don't know what you were like before, you don't know what you're going to be like" (Hughes, 2009, p. 153). This may stem from feeling devalued and disempowered in relation to others (Katsakou et al., 2011), feeling that life has been interrupted by hospital, that there is now a constant threat of return to hospital (Katsakou et al., 2012), or that they are now "beneath" others in society (Olofsson &

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Jacobsson, 2001). This demonstrates that for some people, hospital throws their internal worlds into chaos, and they struggle to make sense of the world, and their place in it (Janoff-Bulman, 1992).

People can also experience stigma, arising from judgement from staff; “I felt that the duty doctor could have been more polite, ’cause that sort of made me think that I was a bad person” (Katsakou et al., 2011, p. 280), or judgement from other service users; “a recovering detox patient may mock or laugh at a mental patient” (Quirk et al., 2004, p. 2577). This stigma can become internalised, with service users feeling as if they have done something to cause this situation, or that it is their fault in some way, “I felt like I had done something wrong, that I was a criminal”, Gilbert et al., 2008, p. 8). These quotes show that people’s external worlds are now not to be trusted and also that they cannot trust others’ judgements of them (Janoff-Bulman, 1992), or their own judgements of themselves (Briere & Scott, 2015).

Finally, service users often fear going into hospital again, due to unpleasant experiences on a previous stay (Mayers et al., 2010). These feelings may be due to cynicism and lack of trust, or they may simply reflect a loss of hope, as the environment in which they were placed for support was in fact traumatising.

Discussion

This review has systematically demonstrated that throughout the hospitalisation process, people go through a range of experiences that can be understood as traumatic. Additionally, it has shown that typically people will undergo more than one of these experiences, compounding the trauma. Some of the aspects that lead to traumatic experiences were ones that destroyed an individual’s belief in themselves as in control of their lives (van der Kolk & McFarlane, 1996). The above reinterpretation of the studies showed that having no control over admission, experiencing restraint, sedation or seclusion, and feeling powerless in relation to staff or other service users may shatter an individual’s assumptions about

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themselves as autonomous and worthy of care, and assumptions about others as benevolent (Janoff-Bulman, 1992). The experiences might also leave an individual feeling overwhelmed and unable to process them (Briere & Scott, 2015).

That aspects of inpatient care are experienced as traumatic for some people does not detract from the evidence that shows mental health inpatient support is helpful and containing for others, in the way it is designed to be (Katsakou & Priebe, 2007). However, if even one person experiences a system designed to support as traumatic, this should be acknowledged with them. It is important to ensure that people who receive inpatient care are being asked about their experiences, and offered support if needed. Power imbalances should be considered in relation to this; if people have felt powerless and helpless, it is questionable whether they would feel able to disclose that to those who hold the position of power.

Furthermore, it is possible to look at which elements of hospitalisation are most likely to be experienced as traumatic and consider how the risk of trauma could be reduced. Many people viewed admission as sudden and unexpected, and felt as if they were coerced, whether on a voluntary or involuntary status. Perhaps when discussing admission it is important for staff to remain mindful of the effect of distress on how people process information, and be clear on what the discussion is about. Additionally, on the wards, there have been calls to increase training in prevention of aggression, or de-escalation techniques, such as using verbal redirection to diffuse situations (Essex, 2001). Despite evidence showing that such training programmes are effective (Scanlan, 2010), evidence also suggests that they are often not used and staff fall back to seclusion or restraint to manage incidents (Jacob et al., 2016). However there are studies that show inpatient wards can shift away from the use of seclusion and restraint, with the right support (LeBel et al., 2014).

It is vital that we understand the experience of trauma in the context of inpatient care, and one way to do this is to use an attachment approach. Allen (2005) draws attention to the

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negative consequences that attachment trauma can have. The examples he gives are around child abuse or domestic violence, where typical attachment relationships are disrupted.

However, research has shown that the relationships between staff and inpatient service users can constitute attachment relationships which can be used for positive therapeutic effect. For instance, staff can provide an opportunity to develop a strong attachment bond with service users by providing consistently appropriate, containing responses to their emotional needs (Goodwin et al., 2003).

However, there are potential negative consequences to these attachment relationships. Some research shows an increased risk of suicide immediately following discharge from an inpatient unit (King et al., 2001), which has been explained in terms of the strong attachments that people form with inpatient staff, which are then torn at the point of discharge (Seager, 2014). In some cases, these may be the first positive attachments that people form, as often those who are experiencing mental health difficulties have difficult or traumatic attachment histories. Furthermore, an institution can itself recreate negative patterns of attachment, for instance by seeing several different clinicians at ward rounds, or the above example of discharge (Seager, 2014). Thus, by disregarding our understanding of attachment, services may be inadvertently recreating damaging attachment relationships with the people who most need positive, secure attachments.

It may therefore be beneficial to hold attachment in mind when developing services, for instance by providing a consistent figure to hold the service user's life story in mind, by ensuring positive attachment relationships are available outside of hospital when considering discharge, or by creating a "family-like" environment on wards, where a small number of consistent staff are available for support (Seager, 2014).

It is also important to acknowledge that although the psychiatric model is the dominant model of mental health support in many western countries, including the UK, there

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are other ways to support people experiencing extreme distress. For instance, in Finland, the development of the Open Dialogue approach has changed the way that first episodes of psychosis are understood and supported (Seikkula & Olson, 2003). Rather than taking people into hospital, or providing medication that dampens psychotic experiences, staff talk through these experiences with the service user and their family, thinking about what they might represent, in an attempt to use the crisis therapeutically. In this example, we can see that attachment relationships are maintained, with family and a small group of staff remaining consistently involved throughout the care period. A five year follow up showed that service users who received this style of support had fewer days in hospital, 82% were no longer experiencing psychotic symptoms, and 86% were in work or studying (Seikkula et al., 2006), whereas outcomes in the UK showed that after 10 years of treatment as usual, 46% were no longer experiencing psychotic symptoms and only 22% were in paid work (Morgan et al., 2014). There is now a pilot of Open Dialogue being trialled across NHS trusts in the UK (NELFT NHS Foundation Trust, 2016).

Another alternative to psychiatric inpatient wards is the use of Soteria Houses. Originating in California, the approach involves supporting people experiencing psychosis in a caring, home-like environment (Mosher, 1999). Typically people are supported by staff in an empathic way, with a focus on “being with” a person to develop a meaning in their psychotic experiences (Mosher, 1999). Research has shown that this approach has similar outcomes to the medical approach, without the use of medication (Calton, Ferriter, Huband & Spandler, 2008). In both of these alternative approaches, it is evident that a focus on supporting people while maintaining an awareness of attachment relationships can be beneficial, and potentially be less traumatising.

Finally, and arguably most importantly, it is important to hear guidance from service users themselves; the experts by experience (Noorani, 2013). There are various people who

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have used services who now suggest ways forward for the mental health system (see, Corstens, Longden & May, 2012; Slade & Longden, 2015). An example relevant to inpatient care is the work of James Leadbitter, an artist who has experienced mental health support both in the community and on inpatient wards, and has designed an alternative “day hospital”, called “Madlove” (Leadbitter, 2015). With input from other service users, Leadbitter attempted to design “a safe place to go mad” (Leadbitter, 2015). Although this was an art project, it is an alternative way to hear service users’ voices and to take on board their suggestions.

This review has shown that despite efforts to ensure inpatient care is a supportive, containing environment, some people still experience this care as traumatic. Many of the elements described as traumatic do not have to be; if we maintain an awareness of the impact of attachment, and are mindful of the potential impact of clinical decisions, inpatient experiences can change for the better. Furthermore, the alternatives to medical inpatient care described above show that this approach is not the only, or even the best, way to support people in extreme distress. With approaches such as Open Dialogue being trialled in the UK, perhaps the time is right for a shift in mental health inpatient services.

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Appendix 1-A

Table of included studies

Authors	Date	Methodology	Population	N	Sex	Age (years)	Ethnicity	Country of study
Andreasson & Skäsäter	2012	Phenomenography	Adults who had been compulsorily admitted	12	5 F 7 M	18-65	Unknown	Sweden
Fenton, Larkin, Boden, Thompson, Hickman & Newton	2014	Interpretative phenomenological analysis	Young adults with psychosis	6	1F 5M	18-33	4 White British 1 White European 1 White-African Caribbean	England
Gilburt, Rose & Slade	2008	Thematic analysis	Adults who have experienced admission to psychiatric hospital	19	9 F 10M	25-60+	13 White British 1 White European 3 Black British 2 Asian British	England
Gregory & Thompson	2013	Auto-ethnography	Service user with a professional social care background	1	F	Unknown	Unknown	England

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Hughes, Hayward & Finlay	2009	Thematic analysis	Adults with previous experience of involuntary inpatient treatment	12	7 F 5 M	19-62	Unknown	England
Johansson & Lundman	2002	Narrative interviews Analysis – phenomenological hermeneutic	Adults who had been involuntarily admitted to psychiatric care	5	3 F 2 M	27-49	Unknown	Sweden
Katsakou, Marougka, Garabette, Rost, Yeeles & Priebe	2011	Thematic analysis (part of a mixed methods study)	Voluntarily admitted patients, some who felt coerced into admission, and others who did not	36	18 F 18 M	21-47	20 White 16 Ethnic Minority	England
Katsakou, Rose, Amos, Bowers, McCabe, Oliver, Wykes & Preibe	2012	Grounded theory and thematic analysis	Involuntarily admitted patients interviewed following discharge	59	25 F 34 M	27-47	37 White 14 Black 6 Asian 2 Other	England
Koivisto, Janhonen & Väisänen	2004	Phenomenological	Voluntarily admitted adults	9	Not stated	Not stated	Not stated	Finland
Mayers, Keet, Winkler & Flisher	2010	(Two-phase study) Thematic analysis of focus group Content analysis of semi-structured interviews	Adults either with their own experience of sedation, seclusion or restraint, or being present at the time of sedation, seclusion or restraint of another	Inter-views - 43	22 F 21 M	25-60	Language spoken – 27 Afrikaans 13 English 2 Xhosa 1 Sotho	South Africa
Olofsson & Jacobsson	2001	Narrative interviews Qualitative interpretative	Involuntarily admitted adults due to be	18	12 F 6 M	19-52	Not stated	Sweden

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		content analysis	discharged in the next 3 days					
Quirk, Lelliot & Seale	2004	(Two part study) Combinative ethnography Content analysis of qualitative survey data	Service users, patient advocacy workers and hospital staff (service user quotes are labelled)	Ethnographic study – not stated Qualitative survey - 5169	Not stated	Not stated	Not stated	England
Ridley & Hunter	2013	Qualitative data analysis using NVivo7	Adults with experience of either community Compulsory Treatment Order (CTO) or hospital CTO (Quotes about Hospital CTO are labelled)	49	16 F 33 M	21-63	45 White 4 BME	Scotland
Wyder, Bland, Blythe, Matarasso & Crompton	2015	Narrative summaries that were analysed using NVIVO 9.2	Patients admitted to hospital under an involuntary treatment order	25	11 F 14 M	24-65	Not stated	Australia
Wyder, Bland, Herriot & Crompton	2015	Narrative summaries which were thematically coded using NVIVO 9.2	Patients who had been admitted to hospital under an involuntary treatment order, who were nearing discharge	25	14 F 11 M	25-65	Not stated	Australia

Appendix 1-B

A table noting the elements of trauma in the review papers by page number and line

<p>Subjective understanding Koivisto et al. page (P). 272 line (L). 20, 33 Fenton et al. P. 236 L. 44; P. 237 L. 17 Gregory & Thompson P. 461 L. 19 Wyder, Bland, Blythe et al. P. 185 L. 1 Hughes et al. P 157 L. 32, 36 Katsakou et al. (2012) P. 1173 L. 16 Mayers et al. P. 68 L. 9</p>	<p>Threats to wellbeing Quirk et al. P. 2577 L. 36, 49 Hughes et al. P. 157 L. 25, 36</p>
<p>Repeated trauma Gilbert et al. P.5, L. 15 Koivisto et al. P. 272 L. 49 Gregory & Thompson P. 466 L. 20 Quirk et al. P. 2577 L. 37, 39 Hughes et al. P. 155 L. 24; P. 157 L. 3 Katsakou et al. (2012) P. 1178 L. 44 Johansson & Lundman P. 643 L 48 Mayers et al. P. 67 L. 27</p>	<p>Sudden Wyder, Bland, Blythe et al. P. 185 L. 6 Hughes et al. P. 157 L. 36 Katsakou et al. (2012) P. 1178 L. 26, 29 Johansson & Lundman P. 643 L. 16 Olofsson and Jacobsson P. 362 L. 20 Wyder, Bland, Herriot et al. P. 47 L. 66</p>
<p>Attachment Andreasson & Skärsäter P. 19 l. 37 Katsakou et al. (2012) P. 1178 L. 1</p>	<p>Stigma Gilbert et al. P. 5, L. 51, P. 8 L. 3 Quirk et al. P. 2577 L. 14 Hughes et al. P. 155 L. 24 Katsakou et al. (2012) P. 1173 L. 1; P. 1178 L. 31 Olofsson and Jacobsson P. 362 L. 32</p>
<p>Powerless Fenton et al. P. 237 L. 3 Gilbert et al. P. 4, L.12, 40, P.6 L. 4 & 48 Quirk et al. P. 2581 L. 1 Wyder, Bland, Blythe et al. P. 185 L. 2, 30 Fenton et al. P. 237 L. 60 Hughes et al. P. 155 L. 36; P. 156 L. 49; P. 157 L. 25, 36, 44 Koivisto et al. P. 272 L. 33 Katsakou et al. (2011) P. 278 L. 10; P. 280 L. 42 Katsakou et al. (2012) P. 1178 L. 29, 36, 44 Andreasson & Skärsäter P. 19 l. 44 Mayers et al. P. 67 L. 28 Olofsson and Jacobsson P. 360 L. 50; P. 362 L. 5, 12 Johansson & Lundman P. 643 L. 39 Ridley & Hunter P. 514 L. 1 Wyder, Bland, Blythe et al. P. 186 L. 10, 16 Wyder, Bland, Herriot et al. P. 48 L. 21</p>	<p>Betrayal Gilbert et al. P. 4 L. 44, P5 L. 29 & 39, P. 6 L. 48 Gregory & Thompson P. 461 L. 17 Hughes et al. P. 156 L. 49; P. 157 L. 36, 44 Katsakou et al. (2011) P. 278 L. 9, 14; P. 280 L. 25, 42 Andreasson & Skärsäter P. 19 l. 41 Katsakou et al. (2012) P. 1178 L. 11, 44 Mayers et al. P. 67 L. 20 Johansson & Lundman P. 643 L. 1, 16 Ridley & Hunter P. 514, L. 1</p>

<p>Uncontrollable Koivisto et al. P. 272 L. 33 Quirk et al. P. 2577 L. 27, 36; P. 2579 L. 8; P. 2881 L. 1 Wyder, Bland, Blythe et al. P. 185 L. 30; P. 186 L. 37 Hughes et al. P. 157 L. 36, 44 Katsakou et al. (2012) P. 1173 L. 11; P. 1178 L. 29 Olofsson and Jacobsson P. 362 L. 20 Mayers et al. P. 68 L. 8 Wyder, Bland, Herriot et al. P. 48 L. 34</p>	<p>Shattered assumptions – world is meaningful Gilbert et al. P. 6 L. 26 Hughes et al. P. 157 L. 8</p>
<p>Shattered assumptions – world is benevolent Gilbert et al. P. 4 L. 13, P. 5 L. 1 Fenton et al. P. 237 L. 31, 37; P. 238 L. 62 Gregory & Thompson P. 461 L. 14; P. 464 L. 9 Quirk et al. P. 2577 L. 50; P. 2579 L. 40 Katsakou et al. (2011) P. 280 L. 16</p>	<p>Shattered assumptions – self is worthy Gilbert et al. P. 5 L. 35; P. 6 L. 25; P. 7 L. 31, 44, 47, 50 Gregory & Thompson P. 464 Quirk et al. P. 2581 L. 1 Fenton et al. P. 237 L. 1 Wyder, Bland, Blythe et al. P. 186 L. 16 Hughes et al. P. 155 L. 20, 30, 36, 49; P. 157 L. 8 Katsakou et al. (2011) P. 278 L. 10; P. 280 L. 1, 14, 51 Olofsson and Jacobsson P. 362 L. 12, 43 Johansson & Lundman P. 643 L. 22, 49 Wyder, Bland, Herriot et al P. 48 L. 23 Katsakou et al. (2012) P. 1178 L. 52</p>

Appendix 1-C

Notes for contributors to Journal of Loss and Trauma

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Section Two: Empirical Paper

**“It’s all changed completely”: How posttraumatic growth following psychosis becomes
part of an individual’s life story**

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Abstract

Research has shown that psychosis can be a traumatic experience, and can lead to on-going distress. Additionally, research investigating the links between mental health and trauma often looks at the potential negative consequences of trauma, such as psychological or emotional distress. However, little research has investigated the potential positive outcomes of experiencing psychosis, such as posttraumatic growth (PTG). To date four studies have investigated whether psychosis could lead to PTG, each of which took place a short time after a first episode of psychosis. This study aimed to learn if the growth people experienced soon after experiencing psychosis remained with them over time. Seven people with an experience of psychosis that they felt led to positive change were interviewed. Narrative analysis was used to unpack participants' stories, revealing a clear structure of the stages that individuals moved through; Preface – A Time of Difference; Chapter 1 – The Crisis: Lost Connections; Chapter 2 – Acceptance and Connections; Chapter 3 – Life Now has Transformed; and the Epilogue – Looking Forward. The characters that supported individuals to reach PTG were also apparent. These narratives have provided some idea of how PTG occurs following psychosis, and what it might feel like. With regards to clinical implications, the study has shown that it is important not just to consider the potential traumatic elements of psychosis, but also to create space to talk about areas of growth.

Keywords: *psychosis, posttraumatic growth, narrative*

“It’s all changed completely”: How posttraumatic growth following psychosis becomes part of an individual’s life story

Much of the research regarding trauma and mental health has looked into the negative psychological consequences of trauma. For instance, evidence suggests that childhood trauma can play a role in the development of psychosis (Varese et al., 2012), and bipolar disorders (Aas et al., 2016). While an important area of study, this focus on negative outcomes of trauma may lead us to neglect other possible outcomes; that positive changes, or growth, can occur in addition to the suffering caused by trauma (Tedeschi & Calhoun, 2004).

Moving away from clinical research, there have been stories throughout history of the possibility of developing in a positive way following traumatic experiences. For instance, Christianity teaches about the transformative powers of suffering through the story of Christ’s ascension following crucifixion, while Greek mythology depicts the Phoenix bursting into flame, only to be reborn from the ashes. Philosophers and teachers often described the connection between difficult experiences and a strengthening of positive experiences; for instance, in “The Prophet”, Khalil Gibran (1926/2005) discusses sorrow’s inextricable relationship with joy; “the deeper that sorrow carves into your being, the more joy you can contain”. Within research, these positive aspects of trauma have been understood in different ways, as adversarial growth (Joseph & Linley, 2005), or stress related growth (Park, Cohen & Murch, 1996). One influential area of research is that into posttraumatic growth (Tedeschi, Park & Calhoun, 1998/2008).

Posttraumatic growth (PTG) is a positive change that occurs following a trauma that challenges a person’s understanding of themselves and the world. It is and indicates that a person has grown beyond a previous level of functioning (Zoellner & Maercker, 2006).

Tedeschi and Calhoun use the metaphor of an earthquake destroying buildings, but following the earthquake, structures can be rebuilt in new and better ways, and may even be earthquake

Posttraumatic growth following psychosis

resistant (Tedeschi & Calhoun, 2004). Similarly, following a trauma, some people's beliefs can be shaken or even damaged, but they can rebuild their beliefs, changed so that they are able to accommodate the trauma in a way they were previously unable to. The theoretical understanding of PTG therefore is based around the idea that people have assumptions about the world that are shattered by trauma (Janoff-Bulman, 1992). It is the attempt to redevelop these assumptions following a trauma that leads to growth (Tedeschi & Calhoun, 2004).

Research into PTG has demonstrated that the growth people tend to experience can be categorised into five broad areas, although it is possible that people may experience change lying outside these categories (Calhoun & Tedeschi, 2004). An individual may find that their priorities have changed, often because they have a new appreciation for life. This greater appreciation for life may lead people to prioritise things that previously may have given way to work or school, such as time with family, or time spent doing enjoyable hobbies (Tedeschi & Calhoun, 2004). Another area in which people may experience PTG is in the development of closer relationships with other people. This may be because they learn how supportive others are during and after a trauma, or they may become more empathic towards others' difficult experiences (Calhoun, Tedeschi, Fulmer, & Harlan, 2000).

People may also experience PTG as a change in their understanding of themselves; seeing themselves as stronger or more resilient than they were prior to the trauma. We can relate this to the earlier metaphor of an earthquake; following the destruction, buildings can be built which are stronger than before, and similarly, following the trauma, a person's adjusted beliefs about themselves and the world might include the understanding of themselves as a "survivor" (Tedeschi, Park & Calhoun, 1998/2008). Another aspect of change within people is the realisation of new directions for their lives, for instance, a person surviving a natural disaster may become a rescue volunteer, or a person who survived cancer may go on to train in the medical profession.

Posttraumatic growth following psychosis

A person may also experience PTG in the domain of the spiritual. For some, a pre-existing faith may be strengthened, while others who had not previously been religious may become more so (Tedeschi & Calhoun, 2004). Still others may not join an organised religion, but may become more spiritual in other ways, for instance, becoming closer to nature, or developing a more philosophical, questioning way of life (Tedeschi & Calhoun, 2004).

When considering what constitutes a traumatic experience, Calhoun and Tedeschi (2004) acknowledge the subjective elements of trauma. Other trauma researchers have also developed similar understandings of trauma, for instance Pearlman and Saakvitne (1995) describe it as a subjective threat to life, bodily integrity, or sanity. Alternatively, Briere and Scott (2015, p. 10) suggest that “an event is traumatic if it is extremely upsetting” and “at least temporarily overwhelms the individual’s internal resources”. When considering trauma from this wider perspective, it is apparent that an extensive range of experiences may be considered traumatic, meaning that PTG has been investigated in relation to a wide range of experiences, including car accidents (Wu, Leung & Cho, 2016), bereavement (Taku, Tedeschi & Cann, 2015), and physical illness such as cancer or HIV/AIDS (Sawyer, Ayers & Field, 2010).

Although the range of areas in which PTG has been investigated is broad, there has been little research investigating the relationship between PTG and mental health labels such as psychosis. Psychosis is an umbrella term for occurrences when people’s experiences of reality become altered or distorted. This can be experienced as seeing or hearing things that others do not, paranoid beliefs, or disordered thoughts (Andresen, Oades & Caputi, 2003). People typically experience their first episode of psychosis (FEP) early in their life, between adolescence and early adulthood, at a time when a person’s way of thinking about themselves and the world are still developing (Dunkley, Bates & Findlay, 2013). The experience of psychosis impacts on an individual’s sense of self in various ways. There is the possible fear

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of “going crazy”, highlighted by Jeffries (1977), where a person’s narrative of themselves as a healthy, sane individual is altered into a narrative of unusual experiences, and they must face the resultant challenges to their identity. This fits with the concept of shattered assumptions, where a trauma shatters our fundamental assumptions about the world (Janoff-Bulman, 1992).

In addition to this potential destruction of their world view, people’s psychotic experiences themselves could be traumatic. Simply experiencing things that others do not can be incredibly frightening, particularly when trying to tell the difference between what is “real” and what is not (Tan, Gould, Combes & Lehmann, 2014). People who hear persecutory voices may believe that they are in genuine danger from the voices’ threats of violence (Brunet, Birchwood, Upthegrove, Michail & Ross, 2012). It could be argued that the voices do not constitute an external threat to those hearing them, but as Murphy highlights, “real or imagined, their influence was felt” (2000, p. 18). Those who experience feelings of paranoia may feel isolated (Morrison, Frame & Larkin, 2003). Furthermore, all the changes associated with psychosis may lead to an incredible sense of loss, including a loss of continuing identity, loss of confidence, or even changes to physical appearance due to side effects of medication (Dunkley et al., 2013).

In addition to the distress caused by the experience of psychosis, it is possible that interventions people experience as a response to their psychosis are in themselves traumatic. Intervention may entail strong medication with unpleasant side effects, or it may entail community treatment orders, involuntary hospitalisation, or even police involvement (Morrison, Bowe, Larkin & Nothard, 1999). If people are hospitalised, they may be restrained or medicated against their will, leaving them feeling threatened or unsafe, or they may witness others experiencing restraint and find this distressing (Mayers, Keet, Winkler & Flisher, 2010). Each of these experiences may individually be traumatic, and often a person

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will go through more than one of the experiences, multiple times, thus compounding the trauma (Morrison et al., 2003).

Traditionally, “recovery” from psychosis has been considered in terms of “symptom reduction” (Kelly & Gamble, 2005), however, an alternative to this clinical view is the concept of personal recovery, which will look and feel different for each person (Anthony, 1993). Previously, studies have shown that personal recovery from psychosis can include an element of transformation or growth (e.g. Andresen et al., 2003; Pitt, Kilbride, Nothard, Welford & Morrison, 2007), however, to date, there are only four studies that conceptualise this within the framework of PTG (Dunkley & Bates, 2014; Dunkley, Bates, Foulds & Fitzgerald, 2007; Mapplebeck, Joseph & Sabin-Farrell, 2015; Pietruch & Jobson, 2012).

Recovery and PTG are similar concepts, however, it is important to note that PTG entails more than recovering to a previous level of functioning, and also that PTG does not negate the negative impact of trauma, but acknowledges that positive change can exist alongside current distress (Tedeschi, Calhoun & Cann, 2007). If we accept that psychosis can shatter a person’s world view, it follows that they will need to develop a new world view or story that accommodates their unusual experiences. It is likely that this different story would encapsulate elements of PTG, such as appreciating life in a new way, or feeling stronger in themselves for having endured such a difficult and unusual experience.

Very few studies have investigated the possibility of PTG following an experience of psychosis. The study by Dunkley et al. (2007) indicated that psychotic experiences were distressing, and participants did identify elements of PTG. Dunkley and Bates (2014) found that following an experience of FEP, growth was an integral element of people’s recovery. A quantitative study found that self-disclosure about psychotic experiences was associated with higher levels of PTG (Pietruch & Jobson, 2012). Most recently, an interpretative phenomenological study showed that people can experience growth following an episode of

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psychosis (Mapplebeck et al., 2015). However, the first three studies were carried out within three years of a person experiencing FEP, while the study by Mapplebeck et al. (2015) did not state the length of time since FEP for the participants. Although it is apparent that PTG is possible following FEP, it is unclear from the current knowledge base whether this remains consistent for people, or is more transient or variable.

It is important to note that Tedeschi and Calhoun state that people are less likely to develop PTG if they are still experiencing trauma (Tedeschi & Calhoun 2004). A few months after a FEP, a person is still likely to be learning how to manage difficult or distressing psychotic experiences (Birchwood, Todd & Jackson, 1998). Additionally, people are likely to still be trying to make sense of their experiences, as suggested by the critical period hypothesis (Birchwood et al., 1998). In this hypothesis, Birchwood et al. suggest that intensive support is most needed in the first two to three years following a FEP. It is at this point that, in England, people should be receiving support from Early Intervention services, which will be influencing how they understand their experiences (Reading & Birchwood, 2005). Dunkley and Bates (2014) suggest that future research could investigate the further nature and trajectory of growth following an experience of FEP. Therefore, this study will build on the current evidence base by interviewing people at least three years after their FEP in order to further develop our understanding of the long term nature of PTG following psychosis. The study aimed to learn if the growth people experienced soon after FEP remained with them over time; that is, if stable PTG could occur, how it appears as an ongoing process, and to what extent it becomes part of an individual's life story.

Cohen, Hettler and Pane (1998/2008, p. 34) state that “analysis of narratives... are ideally suited for the qualitative assessment of PTG”. Additionally, Tedeschi and Calhoun (2004) describe how people often develop a narrative of trauma, describing their life prior to experiencing the trauma, the trauma itself, and how their life changed following it.

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Therefore, this study took a narrative approach, considering participants' stories as a whole, without breaking them into component parts. The research question this study sought to address is, "What are people's ongoing narratives of PTG after psychosis?"

Method

Study Design

A narrative methodology was chosen for this study as narratives are used by people to organise and make sense of their experiences. This need for organisation is understandable if we consider the chaos that can be caused by experiencing psychosis. People use narratives to shape identities and work through identity change (Murray, 2003), such as that caused by psychosis. As Riessman (1993) states, narratives typically occur "where there has been a breach between ideal and real, self and society" (p. 3), and as described above, experiencing psychosis can result in this breach. We also use narrative to frame our worlds (Murray, 2003), and it is this framing and re-storying that allows people to develop new understandings of the world, and so move toward PTG (Tedeschi & Calhoun 2004).

Ethics

Ethical approval was obtained from the Lancaster University Research Ethics Committee. Although many participants were recruited through support groups, they were given the opportunity to contact the researcher separately, to ensure anonymity. Prior to interview, potential participants were screened (discussed further below), and at this point the researcher carried out a semi structured interview based on the positive subscale of the Positive and Negative Syndrome Scale (PANSS) (Kay, Fiszbein & Opler, 1987). This was to ensure that no one was interviewed who was currently highly distressed or confused by their experiences of psychosis. All participants' names have been changed, along with other potentially identifying information.

Recruitment

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Participants were recruited from support groups, online forums relating to psychosis, and networks such as The Hearing Voices Network and The Paranoia Network. Participants were purposively recruited, and were a self-defining, self-selecting population as the study aim was to understand the richness of their stories rather than to generalise to a wide population (Ewick & Silbey, 2003). The researcher contacted moderators of online forums and posted a message describing the study and asking potential participants to contact the researcher. The researcher also contacted facilitators of network meetings and support groups, to ask if she could attend meetings or provide information about the study. The researcher attended two support group meetings, where she described the research and provided information packs, asking potential participants to contact her if they were interested in taking part. Information about the study was also sent to more distant support groups.

Once people expressed an interest in taking part, the researcher carried out a brief screening check to ensure they met the inclusion and exclusion criteria. For all participants, the screening took place over the phone, and involved a discussion of the person's experience of psychosis, why they would like to take part, and an assessment of the current level of risk to self or others. Additionally, the PANSS (Kay et al., 1987) was used to retrospectively assess the potential participants' past experiences to confirm they met the inclusion criteria of a traumatic experience of psychosis. The researcher took note of the person's GP in case they were presenting a risk to themselves or others that necessitated information sharing.

Participants

Seven participants were interviewed; four men and three women. Four participants were recruited from Hearing Voices groups, and three from online forums. The participants ranged in age from 34 to 54, and the time since FEP ranged from three and a half years to 22 years. Participants were included if they had a past experience of psychosis, which they

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considered to be traumatic in some way, and felt they had consequently experienced one or more elements of PTG.

Data Collection

Participants located within 50 miles of the researcher were interviewed in person in a university building or in a community building near to them while participants further than 50 miles away were interviewed via Skype. Informed consent was obtained (see Protocol in Appendix 4-A for details). The interviews were conducted by the researcher, a trainee clinical psychologist. Interviews were conducted using open ended questions in an effort to elicit a narrative (Riessman, 1993). Participants were invited to talk at length, however, prompts were available to assist the creation of a narrative if necessary (See Appendix 4-E for topic guide). The initial question was “Please tell me about your experience of psychosis, starting when you first realised something was different.” Interviews lasted between 42 and 75 minutes and were audio recorded. A research supervisor listened to one interview to check style and technique. Following interviews, the audio data were transcribed verbatim, including detail such as discourse markers, silences and false starts, to stay true to participants’ story telling style, and to maintain the context necessary for analysis (Riessman, 1993).

Data Analysis

As highlighted by Riessman (1993), analysis and transcription are not easily separated. Thus, during transcription and the following reading and rereading of transcriptions, notes were made on the shape that stories took, the similarities and differences between them, and how understanding changed with each reading. Through the course of this, the similarity in the overall plot of each participant’s story began to emerge (Murray, 2003).

Mishler (1986) notes that the purpose of narrative analysis is to flexibly investigate individual stories, rather than to apply one method rigidly across all stories. This is echoed

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by Riessman (1993), who emphasises that there is no one way to perform narrative analysis. Therefore, analysis was informed by the thematic narrative approach described by Riessman (2008), in that the author noted the main events in each narrative, before looking across narratives for similarities and elaborations on these events (See Appendix 2-A). Although participants moved around their stories as they told them during the interviews, certain events appeared in predictable sequences, giving rise to the plot (detailed in each participant's summary story in Appendix 2-B). The plot that emerged was held in mind throughout analysis, for, as Murray (2003) notes "the plot is what gives the narrative account its structure" (p. 98). Analysis was also informed by structural narrative analysis detailed by Riessman (2008), as the author noted the characters in each story along with the function they played, and noted how each participant used the elements of their story to show personal meaning within themes (Appendix 2-A). The below write up follows the plot of the narratives as a whole, as it is this plot that ultimately leads us to the growth that stemmed from participants' experiences of psychosis; the growth that prompted participants to share their stories.

Results

The analysis below describes the importance of characters in each participant's narrative, and the roles that different characters played. It goes on to note the main elements of each chapter, and similarities and differences between narratives. The narratives moved from the Preface – A Time of Difference, where participants first noticed difference, through Chapter One – The Crisis: Lost Connections, where participants began to lose connections with others, and with themselves, to Chapter Two – Acceptance and Connections, where participants rebuilt those connections and accept their lives now. This is followed by Chapter Three – Life Now has Transformed, where participants described how their lives transformed

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following their FEP, and the stories end with the Epilogue – Looking Forward, where participants consider the future.

Dramatis Personæ

Characters were important to each person's story, although they varied in the functions they served. For Bradley, Nathan, Albert and Violet, some of the main characters were family or friends who were involved in supporting them. These "supportive" characters accepted the participants as they were, and worked hard to help them reconnect with others. In doing this, they fostered the beginning of PTG. In contrast, Bernadette and Carl's families gave clear messages that their psychosis was too much to cope with, and asked them to leave the family home. These characters became "obstructive" in that they reinforced the lack of connection felt by these participants, and hindered their path to PTG.

Professionals, such as counsellors and psychologists were "facilitating" characters for Violet, Albert, Carl, Bradley and Sarah, in that they supported these participants to reconnect to themselves, in some cases by facilitating participants to physically reconnect with themselves, and in others by facilitating their connections to their voices or experiences. These facilitators meant that for Carl, Albert and Sarah, their voices became an integral part of their lives, ones which enriched their experiences today, and were a key part of the growth they described.

Finally, services appeared as characters throughout some participants' stories. Although services are made up of multiple people, they often appeared as a single character, one that was either "supportive", such as an Early Intervention service for Bradley, or psychiatric services for Albert and Violet, or they were "obstructive", such as an Early Intervention service for Sarah, or a Crisis Team for Nathan. Similarly, Hearing Voices groups appeared as a "facilitating" character in the stories of Sarah, Carl, Bradley, and Albert, helping them to connect with and understand their experiences.

Preface – A Time of Difference

For each participant, a period of difference occurred before “The Crisis” of their FEP. This period of time was characterised by feelings of fear, paranoia and uncertainty. For instance, Carl began hearing whispering voices, but he “couldn’t make out what they were saying”, leaving him feeling “paranoid” and suspicious of others, particularly family. Albert found himself talking to the equipment he worked with, and then heard “the voices from the equipment back at me”. Bernadette first noticed that she “couldn’t cope with any interaction with people”. This is similar to Violet’s experience, who started to feel people were ganging up on her, and eventually became “paranoid”, thinking that “people were being horrible, probably even when they weren’t”, and also echoes Nathan’s experience, who “just didn’t feel right in society”. Bradley’s initial experience was a traumatic event which he believed had occurred in reality, but which he eventually realised had been a hallucination. This event was followed by years of hurt and pain, until Bradley began experiencing hallucinations again.

For Sarah, the preface showed itself differently, as she had had experiences such as hearing voices all her life, and assumed that this was true for everyone. However, at age nine, she began to realise that others do not hear voices, and began to have a feeling of difference. Around the same time, her voices became more negative than they had previously been. Sarah’s experiences therefore changed at the same time as she experienced a shift in her understanding of herself in relation to others.

Over time, these experiences of difference became more pronounced for participants, as they moved into the next chapter of their lives, The Crisis.

Chapter One – The Crisis: Lost Connections

This chapter was characterised by a feeling of lost connections; participants stopped connecting to themselves, and to others. This separation was understandable as many

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participants suffered scary or traumatic psychotic experiences and overwhelming emotions, leading to suicidal thoughts. It was difficult for participants to seek help at this time, either due to fear of stigma, or because they felt misunderstood by professionals, adding to feelings of lost connectedness. The consequences of their experiences included being made homeless or being hospitalised, therefore losing the safety and familiarity of home and further undermining connections to themselves and others.

As participants' experiences of psychosis became more intense, they began to distance themselves from others. For instance, Nathan's paranoia led him to become "very isolated", and he had "minimal interaction" with others. Similarly, Violet's paranoia led her to skip work, and think that her family was against her; "my sister tried to get me to take some medication, I was actually expecting it to kill me". Bradley also began to keep himself separate from others, walking around town all day; "if I ever bumped into a friend, I'd run the other way (...) I was trying to keep myself away from everyone". Bernadette began to believe she could hear thoughts of other people wanting to sexually abuse her, and became more and more withdrawn.

As well as losing connections to others, participants began to lose connection with themselves; "my mind couldn't understand what had happened, I couldn't understand what had happened" (Bradley). Violet described the day before she attempted to commit suicide, and talked about some of the bizarre things she did, which she still finds confusing; "I threw my glasses on the floor, don't ask me why, I pulled a bogey out of my nose (...) don't ask me why now". Sarah also experienced this loss of connection, and felt that services often made this worse; "I often think that the main struggle that people have, and often it's then intensified in mental health services, is the lack of connection, with themselves and with their emotions, and with other people and with meaningful activities".

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Each participant had very difficult psychotic experiences or overwhelming emotions; “I’ve probably blotted a lot of memories out of my head, probably for my own safety (...) ‘cause it was really traumatic” (Bernadette); “a really overwhelming experience of (...) really powerful emotional states where my experience of myself was pretty fragmented” (Sarah); “it was a very bizarre, very scary place to be” (Bradley); “I feared [the voice] would kill me” (Albert). These experiences led to suicidal thoughts or actions for Sarah, Nathan, Violet and Carl; “I became suicidal, and it got that bad that I even attempted it” (Carl).

Participants often struggled to ask for help at this time, for instance, Carl worried about what others would think after looking up information on the internet around psychosis; “I kept seein’ stuff on the media about lunatics an’ psychopaths (...) well I don’t really wanna be admittin’ to this do I?” When Carl did talk to psychiatrists, he remembers them saying the voices were due to his drinking, rather than hearing his explanation; “I started drinkin’ because I were hearin’ the stuff”. Similarly, Sarah was told to take medication to remove the voices, but she felt that it would be more helpful to understand the voices, as she saw them as part of her identity.

As a result of their experiences, Carl and Bernadette were made homeless, as family “couldn’t take any more” (Carl). Although Violet, Albert and Nathan were not asked to leave home, they were still given messages that their psychosis was too difficult to cope with; “a lot of friends dropped off when I went through this” (Nathan), again indicating a loss of connection with others. Another consequence of these experiences was being taken to hospital, which some people found helpful; “I thought that was the safest place to be” (Albert), but others experienced as scary; “I only stayed there a weekend, because I hated it” (Bernadette).

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Although this chapter in participants' lives was characterised by loss and fear, and felt overwhelming, the participants all came through it, and found in the next chapter that their lost connections could be formed again, and their lives would not always be ruled by fear.

Chapter Two - The Shift: Acceptance and Connections

This chapter in participants' narratives represents a time when connections were forged again, and participants began to accept their new lives. The chapter was peopled with characters who helped them reconnect to others. Participants also found words for their experiences, and began to accept them as part of themselves. It was apparent in the third chapter (described below), that growth could not have occurred without this reconnection and acceptance.

The characters that helped each participant reconnect varied. For Sarah, a mental health physiotherapist helped her to reconnect to herself, and “find a way to being less fragmented”, which allowed her to attend Hearing Voices groups, and “come back to my initial instinct (...) this is ok to hear voices”. A psychologist helped Albert reconnect to himself by encouraging him to “accept [the voices] and work with them”. Albert began to reconnect to others through the Hearing Voices group he attended, again supported by his psychologist. Carl had a similar experience, after telling a counsellor he heard voices, they referred him to a Hearing Voices group, where he received “empathy and understanding”, and felt “normal there”. Nathan also appreciated the normalising support of the Hearing Voices group; “I feel I can walk in society again”. Nathan also received support from the Soteria Network, which he felt helped him to “see people as not dangerous (...) just helping someone who's not well”.

Bradley found the support from Early Intervention allowed him to reconnect to himself and the world, as he went every week, “talking, sharing, offloading”. Alongside this, he felt his parents helped him to regain trust for others, by visiting him daily in hospital and

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allowing him to live with them when he left. Violet had a similar experience, as she moved in with her parents following discharge from a physical health hospital after her suicide attempt, and spent time watching her father; “I started seeing myself in a more positive light, because of the fact that he was caring for me, and (...) I was looking at his example and then starting to behave like he did”.

Bernadette began to reconnect through the church, as she was introduced to Catholicism and witnessed acts of kindness. She then decided; “because of the kindness, I wanted to be kind to other people”. In addition to this kindness, Bernadette had come to accept her experiences of psychosis as the way in which she found God, whom she believed was present during those moments.

This time of reconnection and acceptance was a key step on participants’ journey to the current chapter of their lives; one where life is different from what it was before, but where that difference is viewed with pleasure and gratitude.

Chapter Three – Life Now has Transformed

After Chapter Two, the participants described how their lives had transformed following their FEP. Some of this transformation involved losses, or life being harder in some way. However, there were also positive elements to these transformations, most notably in the form of connections that had been reformed in the previous chapter, and which showed as empathy towards others and themselves, wanting to “give back” to society in some way, and understanding relationships better. Participants’ experiences of FEP led to them being aware of their own vulnerabilities, but at the same time feeling stronger in spite of these. They were often passionate about sharing these experiences of transformation.

Carl and Bradley highlighted losses caused by psychosis; “there is good things that have come from it, but there’s still negatives there” (Carl), “I’m sort of getting back to where I need to be” (Bradley). Sarah described aspects of life that were more difficult following

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psychosis, for instance, not being able to follow the career she had considered, because “there’s so many things that I would have to comply with that I couldn’t, without risking my health (...) and my sanity”. Nathan and Albert had also experienced this shift in future plans; “which I’m not ok with really, but I have to accept” (Nathan).

However, alongside these negatives, all participants described growth that stemmed from their FEP. For instance, Albert stated, “I’m much stronger. I’m much more motivated” when talking about life now compared to before he became unwell. Carl also felt stronger, and acknowledged that although in some ways he was “quite a vulnerable person”, his strength “comes from keepin’ it all going”. Similarly, Nathan acknowledged his vulnerability and strength together; “it’s crazy isn’t it, in this kind of damaged state, I feel stronger in many ways”.

Bradley, Violet, Bernadette and Albert described feeling more confident now than prior to experiencing psychosis; “I’m not scared to try new things now” (Bradley), which related to stepping outside of comfort zones; “I did things that I perhaps wasn’t very comfortable with, and just got more confident really from doing that” (Violet). Confidence also linked to feelings of strength at having survived such difficult experiences; “I’d hit rock bottom (...) it’s time to go back up” (Bradley).

These difficult experiences also led to a sense of empathy for others; “I always buy a big issue, because of being homeless myself” (Bernadette). This empathy may have been present before, but now appeared to resonate more strongly and showed how participants had reconnected to others; “it wasn’t that I didn’t feel, oh dear, that’s not very nice, I just never realised what it was to have a truly awful experience” (Violet). As well as extending empathy and compassion to others, many participants showed this to themselves. For instance, Bradley heard a female voice, but no longer heard his own voice inside his head. He found this frustrating at times, but said “he’s been through a tough time up there, so it’s

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just about patience and letting him know he's not on his own". This empathy towards themselves could also be interpreted as a better connection to the self (discussed further below).

The empathy and compassion had also helped each of the participants to build stronger or better relationships than they had previously; "I think I've got better friends. People who are kind to me, and I'm kind to them, more supportive" (Bernadette). Relationships with others were also enhanced by them being more connected to themselves; "I'm a lot more in touch with my feelings, I sort of understand how communication works a bit better, how other people might be different to me" (Violet).

The deeper connections to themselves, and the acceptance of their experiences mentioned in Chapter Two meant that many participants had learnt from their experiences. For instance, the voices that people heard could indicate when something needed to change; "she's like an alarm system. She's just sorta like telling me that something's not right" (Carl). Sarah felt she had learnt how to be in relationships because she had had a consistently positive relationship with one voice; "the way he's always behaved, acted and engaged with me, has been a really good role model of an equal, solid, connected relationship". Deeper connections also related to the realm of the spiritual; "the world comes alive in a different way when you've got invisible beings and energies everywhere (...) nature comes alive in a different way" (Sarah); "I think there's a lot more meaning to life than what we give credence to" (Nathan); "prayer has come into my life a lot more" (Bradley). Participants described learning how to take care of their mental health following their experiences, for instance, Bradley used counselling skills to talk to his voice and understand its worries, while Bernadette adjusted the spiritual tasks she undertook by giving herself breaks when she needed them.

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Participants further showed their reconnection to others as they described a desire to “give back” in some way, for instance by supporting others at Hearing Voices groups, by praying for others, or by volunteering in some way. For Carl, this gave a sense of “satisfaction (...) I helped someone today”. Participants were also often clear that “I’ve always been quite a caring person” but “I’ve just never been confident enough” (Albert), showing how confidence developed after going through difficult experiences, and showing a shift in noticing and prioritising other opportunities; “now I’m focusing on outside life, focusing on work, focusing on helping people” (Albert); “I think I’ve become less selfish and more holistically motivated, with the rest of humanity” (Nathan).

Some participants described how the positive changes in their lives now had stemmed from their experiences of psychosis; “if that episode hadn’t have happened, I wouldn’t be doing what I’m doing now” (Bradley); “I find a meaning and purpose in life” (Bernadette); “before I had a psychotic episode, I was very unaware of anything” (Violet). For these participants, it was clear that they felt the psychosis had been the catalyst for the transformation of their lives. Other participants did not appear to view psychosis as a catalyst for change, but did described being grateful for their experiences, and to have survived them and reach a different stage of life; “it’s all changed completely and it’s like I’m a completely different person and I really like it” (Albert);

The whole thing, as much as it’s been really traumatic and awful, it’s kind of been magical as well. (...) I mean you can lose your life in psychosis, and people do. But if you get through it, oh it can make you go wow, just those experiences (Nathan).

Epilogue – Looking Forward

Although much of each interview centred around past experiences and how participants came to be where they are now, often they also talked about their hopes for the future, and it was clear they had been thinking about the next chapter in their lives. Some hoped the future

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would consist of “carrying on the same” (Bernadette), and tried to take it as it comes; “I try and take one day at a time, and not rush things” (Bradley). However, alongside this steadiness was an awareness of different possibilities ahead; “there’s loads of stuff I wanna do, but I’m not being impulsive, so I won’t just jump into it” (Albert).

Although many participants had already learned and gained from their experiences, some felt there was more potential; “I’ve got this ongoing hope that there’s more for me to draw from” (Sarah). Furthermore, participants spoke about wanting to learn more about themselves, and to continue furthering their understanding of themselves; “just looking out for new ways of understanding how my mind works” (Violet).

In addition to thinking about the future of their own mental health journey, participants also talked about hoping this research would be helpful for others having similar experiences; “it’ll give people hope that you can recover” (Violet); “it could help ‘em see that there is light at the end of the tunnel” (Carl). Participants also chose to take part in the research in an effort to challenge some of the stigma surrounding mental health and psychosis; “hopefully doing this research makes people realise that we’re just normal people” (Bradley).

Discussion

The narratives showed that each participant experienced growth that exceeded a return to their way of being before experiencing psychosis. The overarching arc of the narrative for these participants is one of challenge, struggle and eventual transformation. Participants’ lives were interrupted by psychosis, and their experience of it was distressing, or sometimes traumatic. They each found ways to survive their experiences, either helped or hindered by characters along the way. Each participant ultimately reached a point of accepting their experiences and reconnecting to themselves and others. This allowed them to recognise the transformation of the stories of their lives.

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Each participant felt that they had deeper or better relationships with family or friends, felt stronger than they had been prior to their FEP, and felt more empathy towards others. Many participants also felt that they were more confident than before. These changes led many participants to want to “give back” in some way to others, a desire they may have had before experiencing psychosis, but which they had not had the confidence to pursue. Some participants also felt they now had new priorities and directions in life. Some participants also experienced spiritual changes, either through the finding of a new religious understanding, or through feeling more spiritually connected to nature. The narratives showed that PTG had occurred for these participants, and had continued to be experienced for many years (up to 22 years for one participant), despite the continuing experiences of psychosis for some participants. This demonstrates what the study set out to find; that not only is growth possible following an experience of psychosis, but that it can remain with people for many years.

The growth described above can be equated with the domains of PTG described by Tedeschi and Calhoun (2004), however, the stories of growth told by participants have also provided some indication of how growth came about, and what it feels like to experience. For instance, one aspect that appeared more nuanced and complex than that captured by quantitative measures of PTG is the change in connecting to the self described by participants. Although this could relate to a change in relationships, in that participants' relationship with themselves had grown, it appears to be more than that. Participants described taking time to reflect on themselves and their day to day experiences, and described these reflections leading to changes in their understanding of the world, for instance, Bernadette feeling closer to God in her experiences, or Nathan realising the kind and caring nature of others. As well as these wider reflections, participants described using their voices

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as a way to understand themselves, or using experiences of paranoia to look out for what in life might be bothering them.

These descriptions show that many participants experienced life in a different way to before psychosis. Furthermore, participants appeared to have found an extra dimension to their experiences, as the experiences enriched their lives in some way. The idea of voices becoming supportive and helpful to voice hearers is not new, and can happen as the result of Dialoguing with Voices (Corstens, Longden & May, 2012). It is perhaps not a stretch to imagine that all experiences of psychosis can lead a person to connect with themselves in a different way, or to learn how to understand and respond to their needs. Most of the participants had attended Hearing Voices groups, so it would be understandable that this idea is familiar to them, as the ethos of the Hearing Voices Network is to make sense of unusual experiences (Dillon & Hornstein, 2013). It should be noted that one participant had not attended a Hearing Voices group, however, she had still learnt to use her feelings of paranoia as an indicator to take care of herself and her mental health.

The participants also acknowledged that although they had experienced growth or transformation, there were still negatives that came from experiencing psychosis. For instance, the participants still had experiences that related to their FEP, such as hearing a voice. Each of them, however, felt they had learnt how to manage these experiences, and, as discussed above, was able to think of them as a message about their needs, and know how to respond to them. Additionally, many participants still struggled at times with the interruption that psychosis had on their life course. This relates to ideas around developmental lifecycle, where certain milestones are expected to be reached by certain developmental stages, for instance, leaving home, finding a partner, getting married and having children (Carter & McGoldrick, 1999). These examples may feel stereotypical, but can be understood as a way of noticing difference (Carr, 2006). In literature around learning disabilities for instance, it is

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noted that families with one member with a learning disability go through lifecycle changes at a different pace to other families, or in a different order (Goldberg et al., 1995). It is apparent from the narratives of the participants in this study that some felt as if they did not reach expected stages at the expected time, and experience understandable feelings of loss as a consequence.

The findings also showed that for participants to reach PTG in spite of these feelings of loss, reconnection needed to occur, to themselves and to others. The loss of connection is supported by other studies into psychosis and PTG (Dunkley et al., 2007), and this reconnection fits with Tedeschi and Calhoun's (2004) theoretical explanation of PTG. When a trauma occurs, it shatters a person's understanding of the world, but then that understanding is rebuilt to accommodate the trauma. Participants in this study described losing connection with themselves as they struggled to understand the new world they found themselves in; a world of terrifying visual hallucinations, of threatening voices, or of paranoia and loss of trust. As they began to understand these experiences in a different way, they were able to accept them and build them into their worldview, allowing them to connect with their experiences and themselves in a new way. This acceptance, of the self, the experiences of psychosis, and the way that life is now, relates to previous findings (Mapplebeck et al., 2015).

Furthermore, Tedeschi and Calhoun (2004) describe the importance of talking with others about traumatic experiences in order to jointly create new narratives and ways of understanding of the world, demonstrating the importance of reconnecting to others. This relates to the work of Lysaker and Lysaker (2002) on the dialogical nature of the self. They argue that the individual is constantly in dialogue with themselves and with others, allowing them to develop a sense of coherence around identity. During an experience of psychosis, however, Lysaker and Lysaker (2002) argue that an individual is unable to maintain this dialogue, or this sense of coherence. It appears that the participants in this study needed to

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reconnect to themselves and others, to restart this dialogue, in order to facilitate a shift towards acceptance and growth.

Clinical implications

This study shows that when working with people with experiences of psychosis, it is important to consider the traumatic elements of their experiences, to ask about these as well as listening for the potential for growth. Simply encouraging discussion around this may provide an alternative possibility for people to consider. The style of discussion will be important, in order for the therapist to support the individual to restart dialogues that support coherency of identity. In addition to listening for positives and negatives of psychosis, it may be beneficial to facilitate the understanding and acceptance of experiences, to further facilitate growth.

When considering current practice, the emphasis on family intervention is of great importance when considering that relationships appear to facilitate growth. When carrying out family interventions, it would be beneficial to ensure space is provided to talk through the development of a different understanding of the world, that includes the experiences of psychosis. Finally, when considering the experiences of psychosis, it is important to remember that many current interventions, including medication, aim to reduce them. However, this may be unhelpful when thinking about PTG, as it appears that incorporating experiences of psychosis into life may well facilitate growth.

Limitations

This study had a small sample, which was purposively selected, so the results are not generalizable; not everyone with psychosis will experience growth, and those who do may not experience it in the way described by the participants in the study. Furthermore, most participants attended Hearing Voices groups, making it difficult to disentangle their views from the ethos of Hearing Voices.

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The researcher's own subjectivity is acknowledged when interpreting the stories told by participants, as stories have not been replicated verbatim, but were interpreted (Riessman, 1993). Additionally, as noted by Bartlett (1920), when stories are reproduced, elements are often changed or left out, especially when the culture of the person reproducing them differs from the culture of the original storyteller. Therefore, the researcher's own culture of working in mental health and not having a personal experience of overt/distressing psychosis is likely to have influenced what was privileged in participants' stories.

Further research

This research demonstrated that PTG can occur following an experience of psychosis, albeit in a small group of people, and that PTG can persist and evolve over many years.

Importantly, it has also begun to consider the process of how PTG emerged; through reconnection and acceptance. Future research could further investigate why and how reconnection and acceptance occurs for some people following psychosis, but not for others. Additionally, it was apparent that PTG can occur alongside psychosis. This study did not interview people who were currently distressed by their experiences, however this may be an interesting area for further investigation, as it may be that PTG can occur alongside distress in mental health. Additionally, as noted above, many participants attended Hearing Voices groups, and may have reflected the ethos of these groups in their experiences. Future research could further investigate the interaction between the ethos of Hearing Voices and the development of stories of PTG, perhaps looking at the extent to which people consciously incorporate these understandings into their own.

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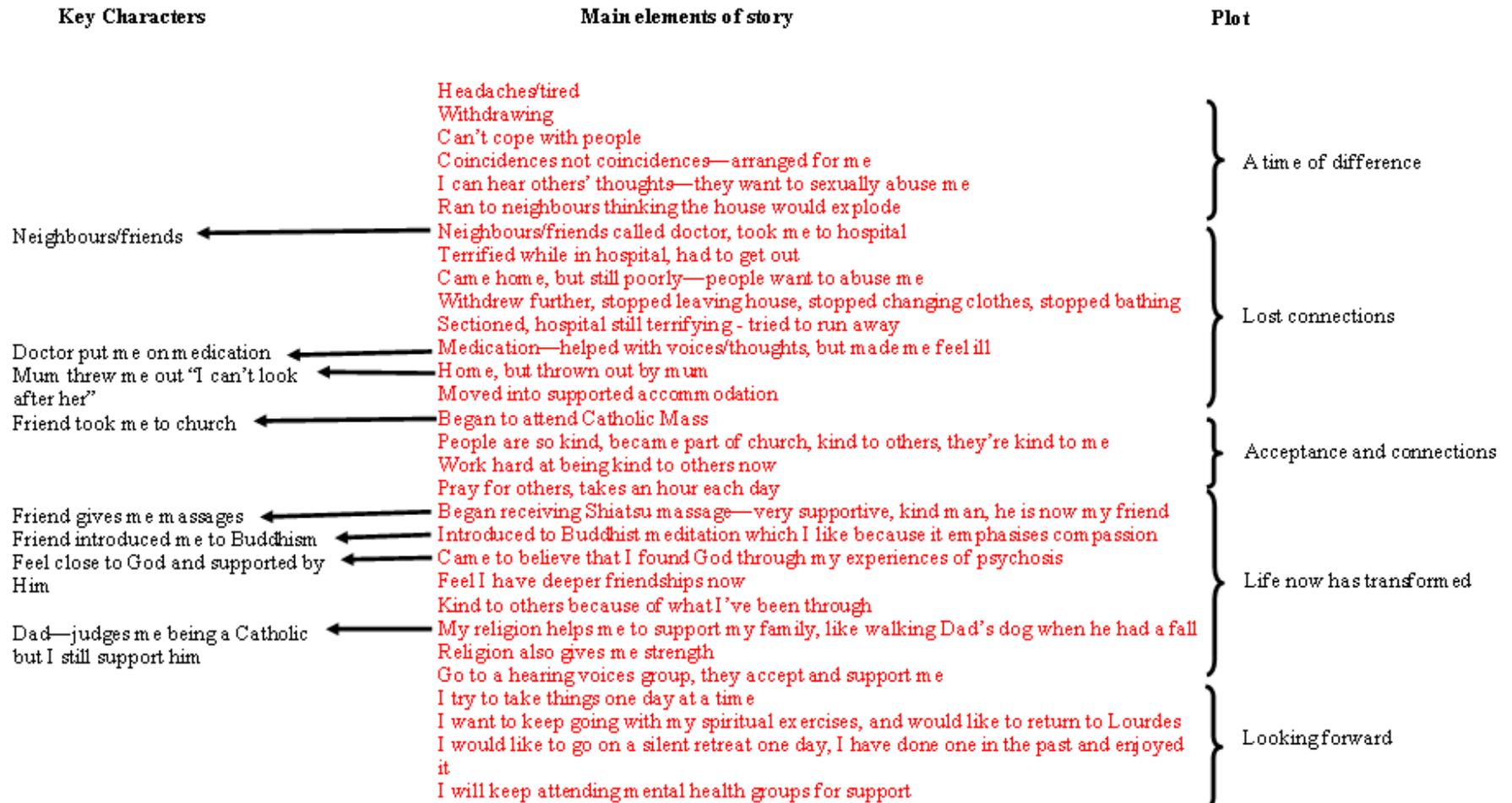
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Appendix 2-A

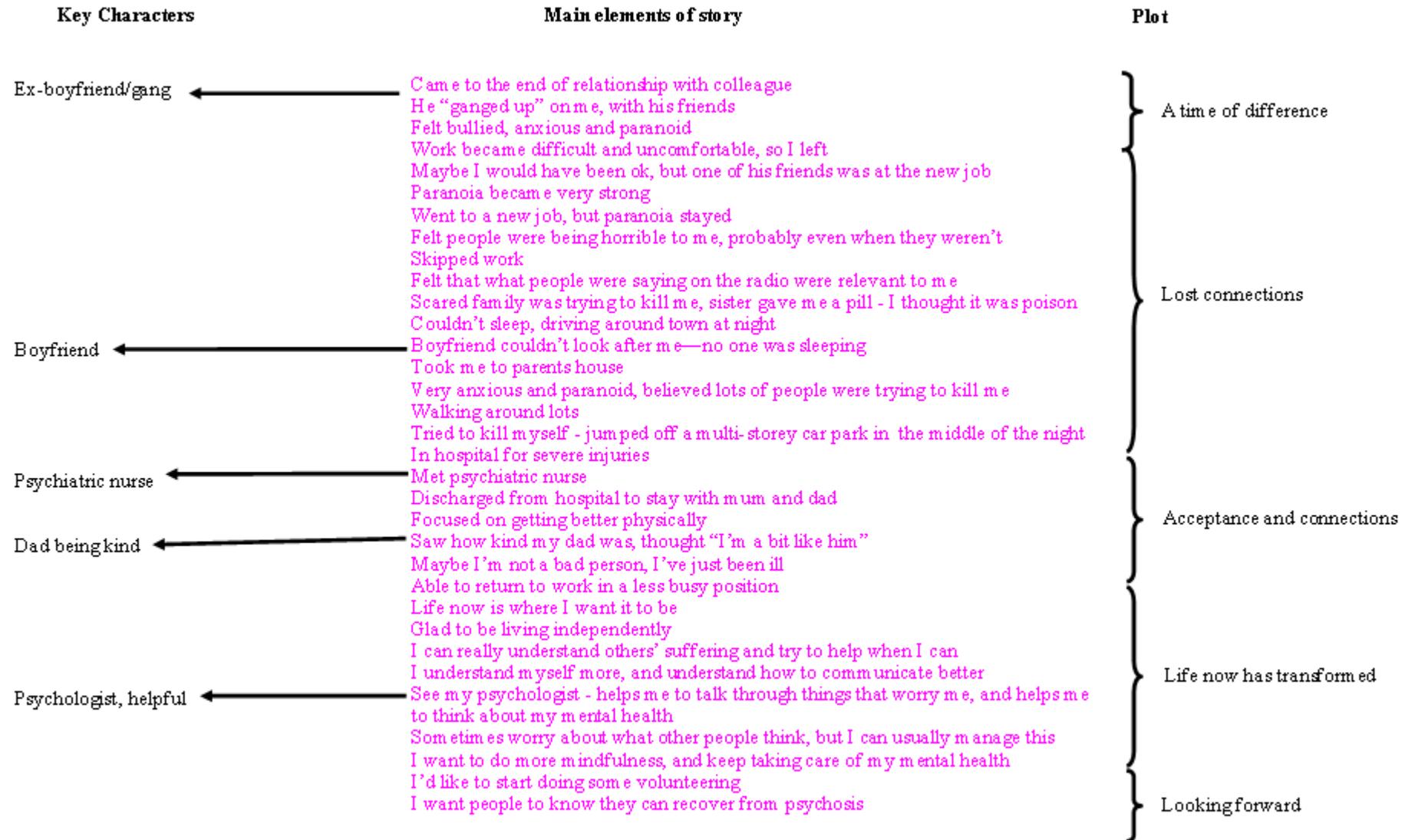
Diagrams showing the structural analysis of individual's stories

Bernadette



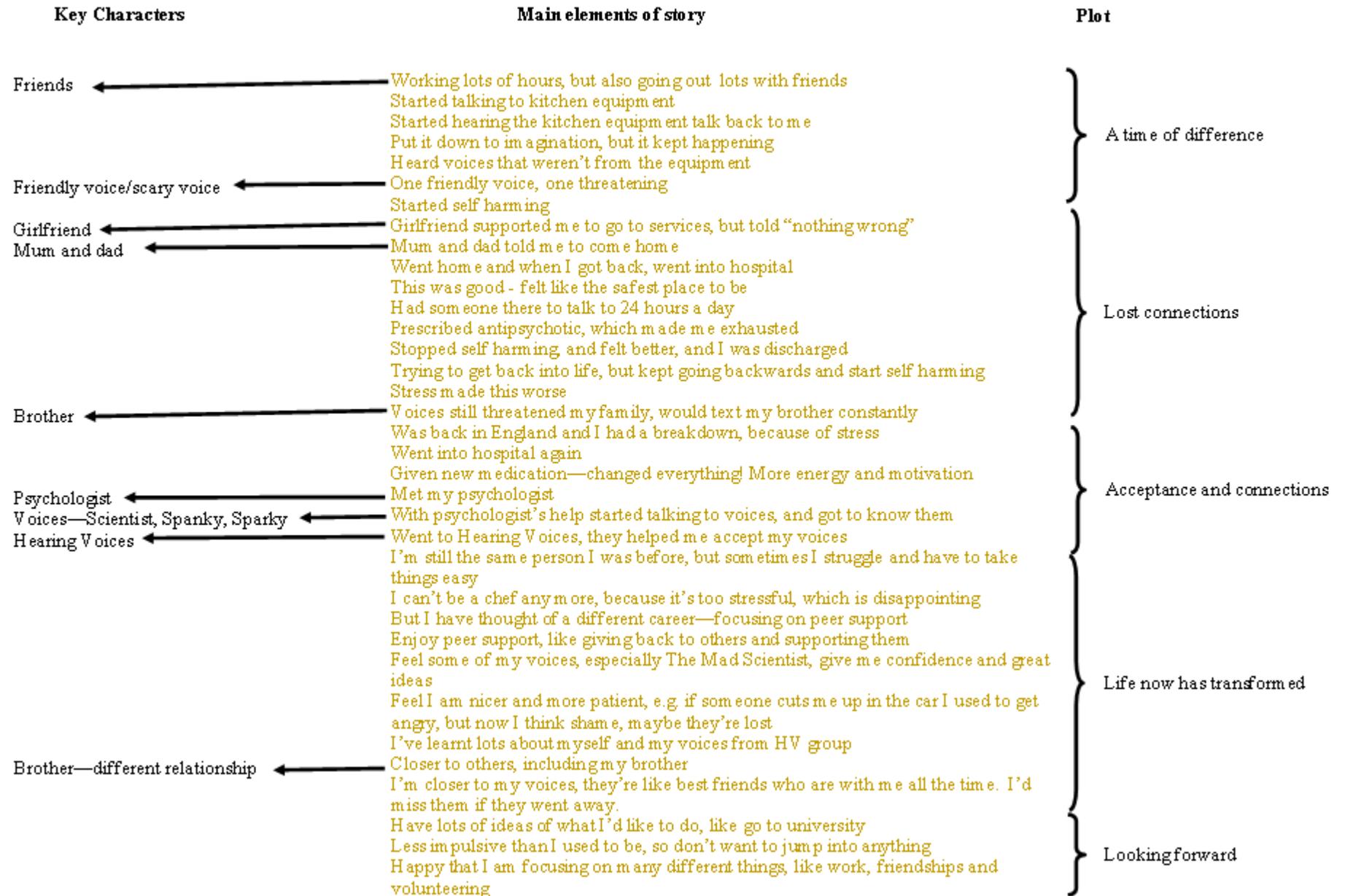
Posttraumatic growth following psychosis

Violet



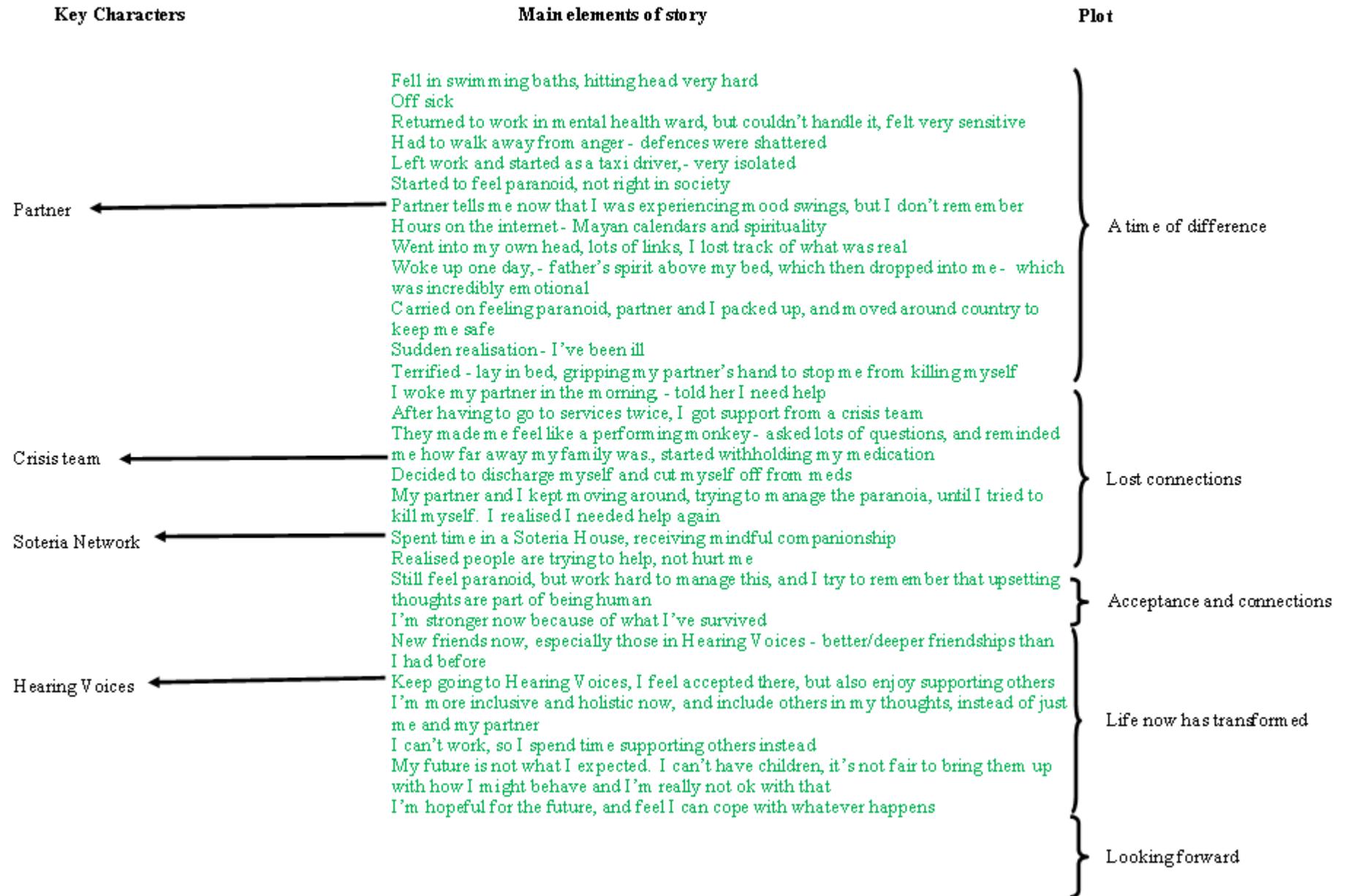
Posttraumatic growth following psychosis

Albert



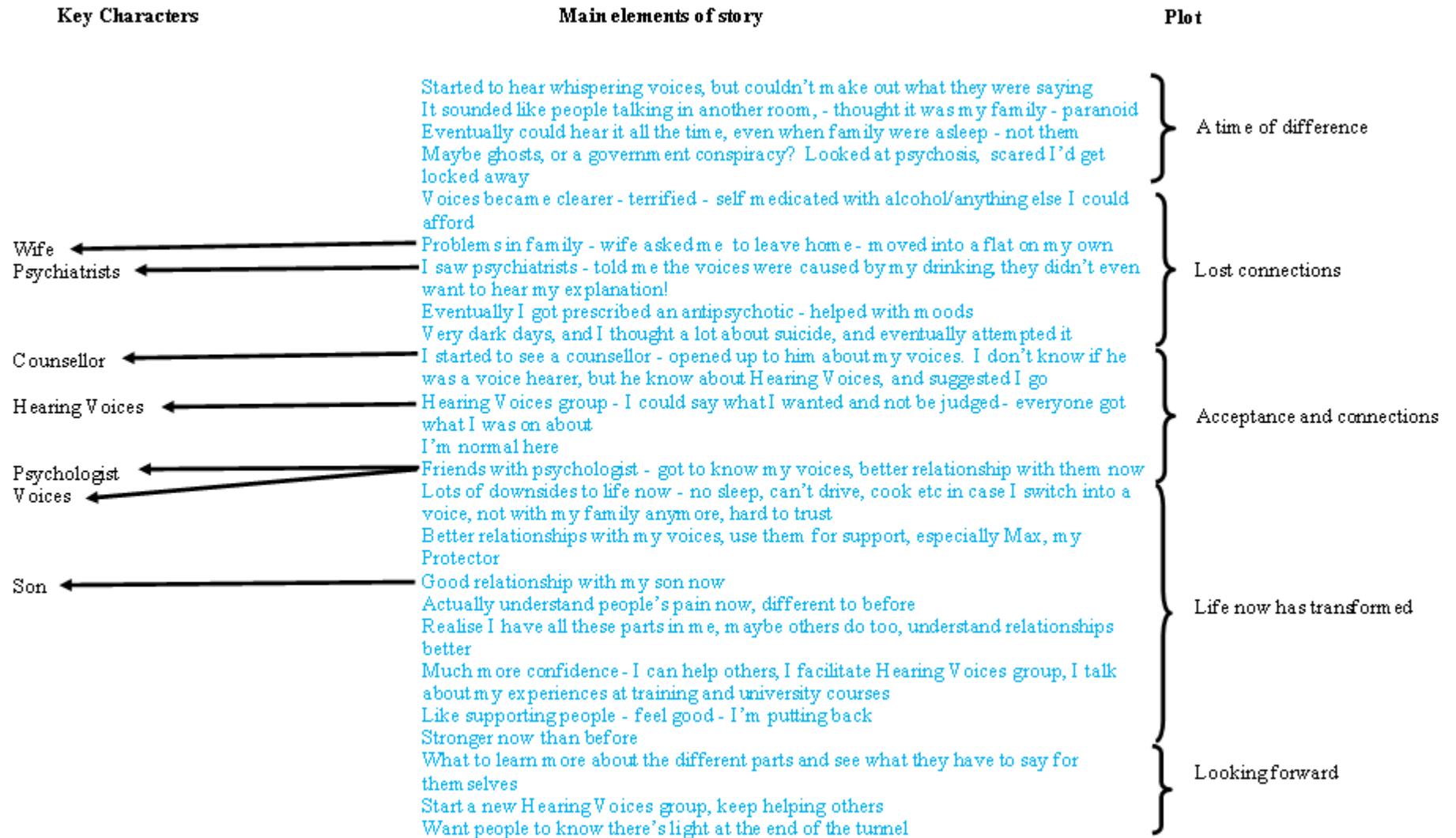
Posttraumatic growth following psychosis

Nathan



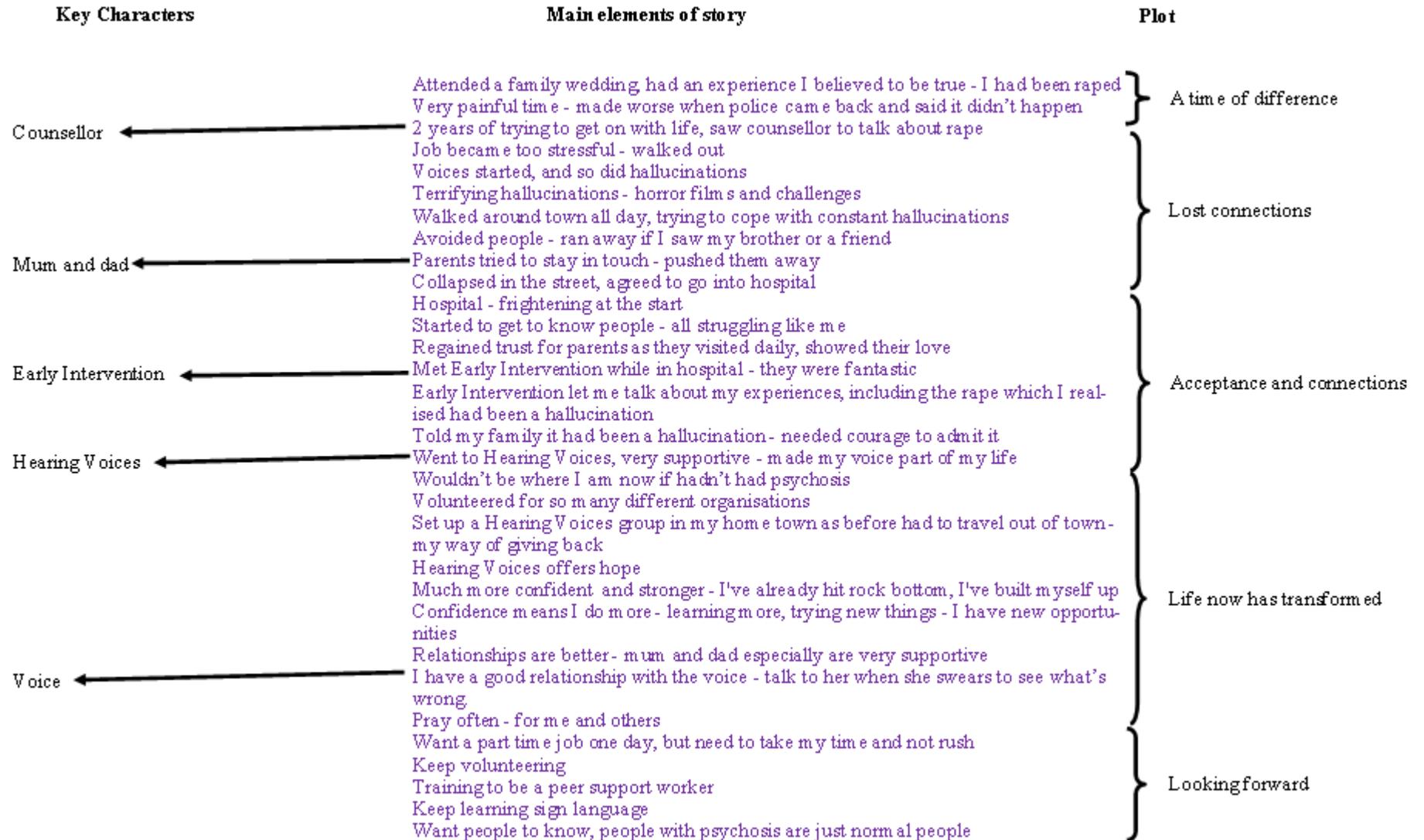
Posttraumatic growth following psychosis

Carl



Posttraumatic growth following psychosis

Bradley



Posttraumatic growth following psychosis

Sarah

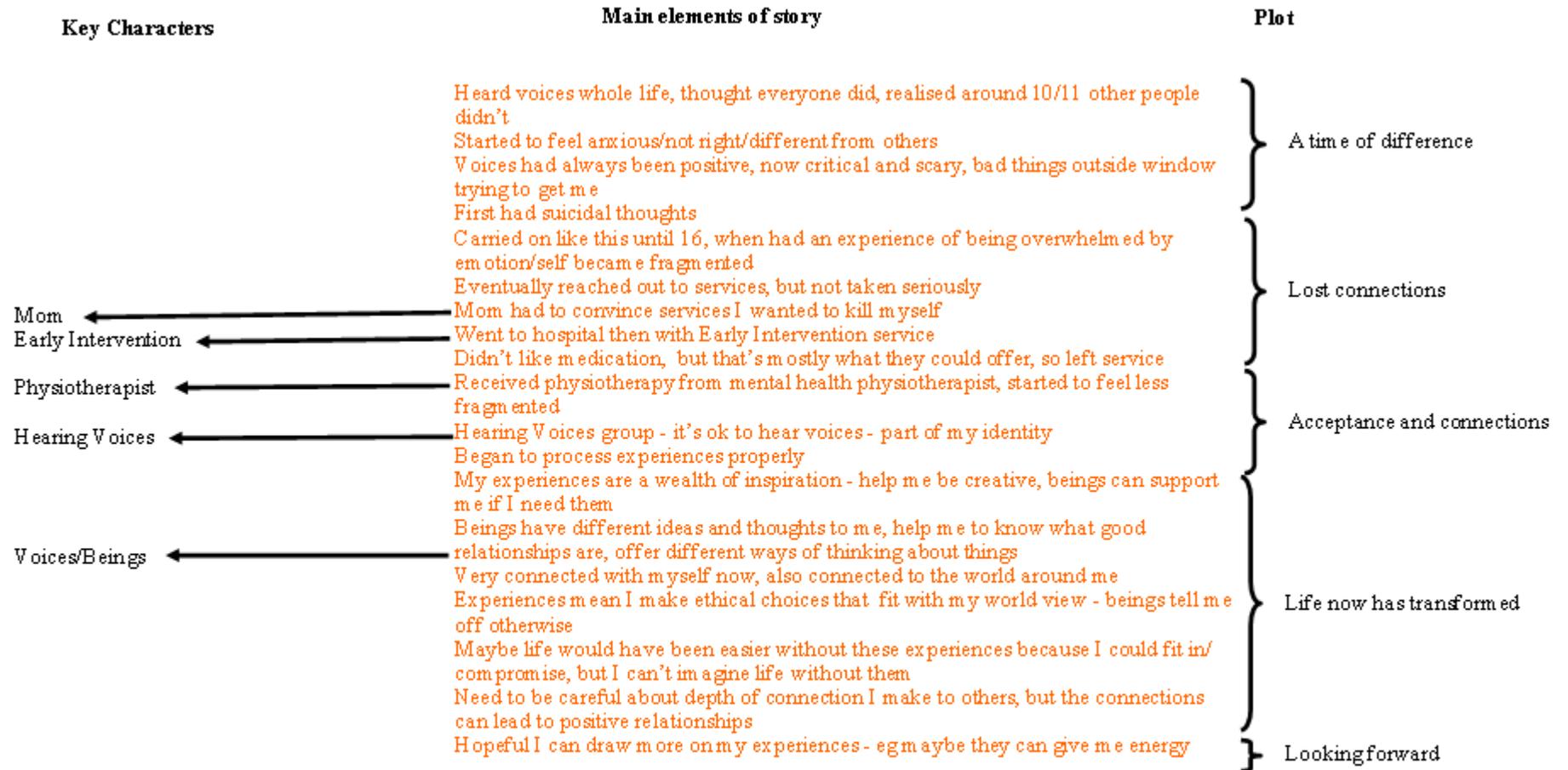


Table showing the development of themes between individual's stories

Acceptance	Reconnections self/others	Positives/negatives life now	Confidence	Empathy	Giving back
<p>Go to a hearing voices group, they accept and support me</p> <p>Saw how kind my dad was, thought "I'm a bit like him"</p> <p>Maybe I'm not a bad person, I've just been ill</p> <p>Went to hearing voices, they helped me accept my voices</p> <p>Keep going to Hearing Voices, I feel accepted there, but also enjoy supporting others</p> <p>Better relationships with my voices</p> <p>Realise I have all these parts in me, maybe others do too, understand relationships better</p> <p>What to learn more about the different parts and see what they have to say for themselves</p> <p>Early Intervention let me talk about my experiences, including the rape which I realised had been a hallucination</p> <p>Went to Hearing Voices, very supportive - made my voice part of my life</p> <p>Hearing Voices group - it's ok to hear voices - part of my identity</p>	<p>People are so kind, became part of church, kind to others, they're kind to me</p> <p>Work hard at being kind to others now</p> <p>Feel I have deeper friendships now</p> <p>Kind to others because of what I've been through</p> <p>Saw how kind my dad was, thought "I'm a bit like him"</p> <p>I understand myself more, and understand how to communicate better</p> <p>I've learnt lots about myself and my voices from HV group</p> <p>Closer to others, including my brother</p> <p>I'm closer to my voices, they're like best friends who are with me all the time. I'd miss them if they went away.</p> <p>Realised people are trying to help, not hurt me</p> <p>I'm more inclusive and holistic now, and include others in my thoughts, instead of just me and my partner</p> <p>Friends with psychologist - got to know my voices, better relationship with them now</p> <p>Better relationships with my voices, use them for support, especially Max, my Protector</p> <p>Good relationship with my son now</p> <p>Relationships are better - mum and dad especially are very supportive</p> <p>I have a good relationship with the voice - talk to her when she swears to see what's wrong</p> <p>Very connected with myself now, also connected to the world around me</p>	<p>Life now is where I want it to be</p> <p>Sometimes worry about what other people think, but I can usually manage this</p> <p>I'm still the same person I was before, but sometimes I struggle and have to take things easy</p> <p>I can't be a chef anymore, because it's too stressful, which is disappointing</p> <p>But I have thought of a different career—focusing on peer support</p> <p>Happy that I am focusing on many different things, like work, friendships and volunteering</p> <p>My future is not what I expected. I can't have children, it's not fair to bring them up with how I might behave and I'm really not ok with that</p> <p>I'm hopeful for the future, and feel I can cope with whatever happens</p> <p>Lots of downsides to life now - no sleep, can't drive, cook etc in case I switch into a voice, not with my family anymore, hard to trust</p> <p>Wouldn't be where I am now if hadn't had psychosis</p> <p>Maybe life would have been easier without these experiences because I could fit in/compromise, but I can't imagine life without them</p>	<p>Feel some of my voices, especially The Mad Scientist, give me confidence and great ideas</p> <p>Much more confidence - I can help others, I facilitate Hearing Voices group, I talk about my experiences at training and university courses</p> <p>Confidence means I do more - learning more, trying new things - I have new opportunities</p>	<p>Kind to others because of what I've been through</p> <p>I can really understand others' suffering and try to help when I can</p> <p>Feel I am nicer and more patient, e.g. if someone cuts me up in the car I used to get angry, but now I think shame, maybe they're lost</p> <p>I'm more inclusive and holistic now, and include others in my thoughts, instead of just me and my partner</p> <p>Actually understand people's pain now, different to before</p>	<p>Pray for others, takes an hour each day</p> <p>My religion helps me to support my family, like walking Dad's dog when he had a fall</p> <p>I can really understand others' suffering and try to help when I can</p> <p>I'd like to start doing some volunteering</p> <p>But I have thought of a different career—focusing on peer support</p> <p>Enjoy peer support, like giving back to others and supporting them</p> <p>Keep going to Hearing Voices, I feel accepted there, but also enjoy supporting others</p> <p>I'm more inclusive and holistic now, and include others in my thoughts, instead of just me and my partner</p> <p>I can't work, so I spend time supporting others instead</p> <p>Like supporting people - feel good - I'm putting back</p> <p>Start a new Hearing Voices group, keep helping others</p> <p>Want people to know there's light at the end of the tunnel</p> <p>Volunteered for so many different organisations</p> <p>Keep volunteering</p> <p>Training to be a peer support worker</p>

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Strength	Spirituality	Medication/Hospital	Suicide	Hearing Voices Group	Disconnection
<p>Religion also gives me strength</p> <p>I'm stronger now because of what I've survived</p> <p>I'm hopeful for the future, and feel I can cope with whatever happens</p> <p>Stronger now than before</p> <p>Much more confident and stronger - I've already hit rock bottom, I've built myself up</p>	<p>Began to attend Catholic Mass</p> <p>People are so kind, became part of church, kind to others, they're kind to me</p> <p>Introduced to Buddhist meditation which I like because it emphasises compassion</p> <p>Came to believe that I found God through my experiences of psychosis</p> <p>want to keep going with my spiritual exercises, and would like to return to Lourdes</p> <p>I would like to go on a silent retreat one day, I have done one in the past and enjoyed</p> <p>I want to do more mindfulness</p> <p>Pray often - for me and others</p> <p>Very connected with myself now, also connected to the world around me</p>	<p>Neighbours/friends called doctor, took me to hospital</p> <p>Terrified while in hospital, had to get out</p> <p>Sectioned, hospital still terrifying - tried to run away</p> <p>Medication—helped with voices/thoughts, but made me feel ill</p> <p>Went home and when I got back, went into hospital</p> <p>This was good - felt like the safest place to be</p> <p>Had someone there to talk to 24 hours a day</p> <p>Prescribed antipsychotic, which made me exhausted</p> <p>Went into hospital again</p> <p>Given new medication—changed everything! More energy and motivation</p> <p>started withholding my medication</p> <p>Decided to discharge myself and cut myself off from meds</p> <p>Eventually I got prescribed an antipsychotic - helped with moods</p> <p>Hospital - frightening at the start</p> <p>Started to get to know people - all struggling like me</p> <p>Went to hospital then with Early Intervention service</p> <p>Didn't like medication, but that's mostly what they could offer, so left service</p>	<p>Tried to kill myself - jumped off a multi-storey car park in the middle of the night</p> <p>Terrified - lay in bed, gripping my partner's hand to stop me from killing myself</p> <p>My partner and I kept moving around, trying to manage the paranoia, until I tried to kill myself. I realised I needed help again</p> <p>Very dark days, and I thought a lot about suicide, and eventually attempted it</p> <p>First had suicidal thoughts</p> <p>Mom had to convince services I wanted to kill myself</p>	<p>Go to a hearing voices group, they accept and support me</p> <p>Went to hearing voices, they helped</p> <p>I've learnt lots about myself and my voices from HV group</p> <p>New friends now, especially those in Hearing Voices - better/deeper friendships than I had before</p> <p>Keep going to Hearing Voices, I feel accepted there, but also enjoy supporting others</p> <p>Hearing Voices group - I could say what I wanted and not be judged - everyone got what I was on about</p> <p>I'm normal here</p> <p>I facilitate Hearing Voices group</p> <p>Start a new Hearing Voices group, keep helping others</p> <p>Went to Hearing Voices, very supportive - made my voice part of my life</p> <p>Set up a Hearing Voices group in my home town as before had to travel out of town - my way of giving back</p> <p>Hearing Voices offers hope</p> <p>Hearing Voices group - it's ok to hear voices - part of my identity</p>	<p>Withdrawing</p> <p>Can't cope with people</p> <p>Withdrew further, stopped leaving house, stopped changing clothes, stopped bathing</p> <p>Sectioned</p> <p>Home, but thrown out by mum</p> <p>Felt people were being horrible to me, probably even when they weren't</p> <p>Skipped work</p> <p>Boyfriend couldn't look after me</p> <p>Very anxious and paranoid, believed lots of people were trying to kill me</p> <p>very isolated</p> <p>Started to feel paranoid, not right in society</p> <p>Maybe ghosts, or a government conspiracy? Looked at psychosis, scared I'd get locked away</p> <p>Problems in family - wife asked me to leave home - moved into a flat on my own</p> <p>Walked around town all day, trying to cope with constant hallucinations</p> <p>Avoided people - ran away if I saw my brother or a friend</p> <p>Parents tried to stay in touch - pushed them away</p> <p>Hospital - frightening at the start</p> <p>Started to feel anxious/not right/different from others</p> <p>self became fragmented</p>

Appendix 2-B

Summary Stories

Bernadette's Story Summary

Dramatis personæ (in order of appearance in interview)

- Bernadette - main character. Her story is described below
- Mum - Bernadette's mother. Supported her initially through her psychosis, but then asked her to leave the family home. Mum feels that Bernadette is ill because of the medication she takes, and if she stopped taking it, she would no longer be ill
- God - Bernadette became a Catholic in the first few years after her first experience of psychosis. Religion is very important to her, and she believes that God was present in her moments of psychosis, and that is how she found Him.
- Friend - Bernadette receives Shiatsu massage from this friend. He is very supportive of her, and Bernadette trusts him and feels safe with him. He also introduced her to Buddhist meditation.
- Dad - Bernadette's father. He was physically violent towards Bernadette and her mother when Bernadette was a child. He now laughs at her experiences, along with other members of her family, saying "you hear voices that tell you to get a job".

Preface – A Time of Difference

Bernadette remembers not receiving support during the first 1½ years of psychosis. During this time, she had frequent headaches and felt tired. Eventually she reached a point where she felt she could not cope with any interactions with people. She felt that coincidences were in fact arranged specifically for her. She also could hear other people's thoughts, thoughts of wanting to sexually abuse her. She ran out of the house one night, believing that the gas was leaking and that her house was going to explode.

Chapter 1 - The Crisis: lost connections

At this point, in 1995, Bernadette voluntarily went into hospital. However, she found this experience terrifying, as she was on a mixed ward, and remembers one particular man who only wore a sheet and would occasionally expose himself to others. Bernadette only stayed

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on the ward for a weekend on this occasion. On her return home, she continued to believe that others wanted to sexually abuse her and became more withdrawn, eventually stopping bathing, changing her clothes, and eating. At this point, Bernadette was admitted to hospital on a section. She returned to the same ward, where she was very frightened, and kept trying to escape. She refused medication, and was held down by staff and injected. She was put on an antipsychotic, which stiffened her muscles, and blurred her vision. With support, she came off the medication and returned home, however, 9 months later, her experiences returned and she was sectioned again. She was placed on a women's only ward and resumed taking medication. She returned to the community, and continued on her medication, which she still takes. She struggled with accommodation at this time, as her mum threw her out. Bernadette has blotted out many memories of this time, because it was so traumatic.

Chapter 2 - The Shift: acceptance and connections

When Bernadette first started having psychotic experiences, a friend took her to a Catholic care centre which provided counselling, and daily Mass. While there, Bernadette noticed how kind and accepting this group of people were, both to her, and to others who were struggling. She also met people who had had problems of their own, but who had recovered and were now focused on helping others. A link was made, and on her return to her home town, she visited a Methodist church, and a Baptist church, before finding her home in the Catholic church, and becoming a Catholic 2 years later. She attends Mass regularly, has been on retreats, and has twice made a pilgrimage to Lourdes.

Chapter 3 - Life Now is Bittersweet

Bernadette feels that the kindness shown to her by those in the church has influenced her to be kind to others. She shows this kindness in different ways, for instance, having been homeless, she supports big issue sellers, or often buys hot drinks for those living on the street.

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Bernadette also prays daily for other people, and tries to show kindness and compassion in all areas of her life.

Bernadette receives Shiatsu massage from a friend, and through him has also become interested in Buddhist meditation. She feels this fits well with her Christianity, because it emphasises compassion. She still struggles with suicidal thoughts, but has found that meditation can help with these, as she has learnt not to hold onto the thoughts. Bernadette feels that she would not have come to her faith had she not experienced psychosis, and feels it is important to look for God in difficult experiences.

She has made many friends through the church, and through attending meditation sessions, and tries to support them and help them in whatever way she can. She feels that these friendships are deeper than they were before she experienced psychosis. Although her family have not always been supportive, she tries to remain kind and compassionate to them and is guided by her religion in this. Bernadette also attends a hearing voices group, where she can talk about her experiences, and receive acceptance and support.

Afterword - Looking Forward

Bernadette finds that things are easier if she takes life one day at a time. She is currently undertaking the spiritual exercises of St. Ignatius of Loyola, and would like to continue with these, alongside her other prayers, and her Buddhist meditation. She is also planning on continuing to attend mental health groups. She would like to do a silent retreat in the future. Bernadette took part in the study because she thinks that it is important to support “any advancement in the treatment of mental illness”.

Violet's Story Summary

Dramatis personæ (in order of appearance in interview)

- Violet - main character. Her story is described below
- Dad - Violet's father. He took care of her following her experience of psychosis, providing support while she lived with him and her mother. During this time, he was also caring for Violet's mother, who had Alzheimer's.
- Psychologist - Violet began seeing a psychologist a few years ago, and still sees her around once a month. This psychologist is helpful in that she provides space for Violet to talk, but also often provides alternative ways of thinking about worries or concerns that Violet has.

Preface – A Time of Difference

Violet feels her difficulties first began with the end of a relationship with a colleague. As the relationship ended, Violet felt that neither person handled it well at first, but then remembers her ex partner and his friends starting to gang up on her. She went to a new job, but unfortunately, a person from her previous workplace had also begun working there, and at this point, Violet began feeling paranoid.

Chapter 1 - The Crisis: lost connections

Violet moved to another workplace, however, the experiences of paranoia remained, for instance feeling that colleagues were being horrible to her. She began skipping work, and noticed that things on the radio were becoming relevant to her. She felt that her family were against her, and that they may be trying to kill her. She was struggling to sleep, and would often take the car and drive away from home, so that her boyfriend would need to come and look for her. She is not sure why she did this, but remembers feeling afraid and paranoid. Her boyfriend eventually took her to stay at her parents' house, as he could no longer look after her. Violet was very distressed at this point, believing various people were planning to kill her. She walked to a nearby multi-storey car park, and jumped off, with the intention of killing herself. Violet was in hospital for several weeks due to her physical injuries, and

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during this time was visited by a psychiatric nurse, who prescribed an antipsychotic. Violet left hospital and lived with her mother and father.

Chapter 2 - The Shift: acceptance and connections

After leaving hospital, Violet found she had to focus on her physical recovery, rather than spending time thinking about being a bad person. She was able to take several months off work, and felt that she had no pressure to interact with people until she felt ready. She spent time watching her dad interact with others, and noticed how he was a good caring person, and began to see herself in this light, and behave in the way he did. When she did return to work, her employers found a less stressful role, where she could focus on documentation. It was during this time that Violet realised “I haven’t been well” and found this a relief, as it shifted her thinking of herself as a bad person.

Chapter 3 - Life Now is Bittersweet

Violet feels that it has taken her a long time, but that her life now is nearly back to where she wants it to be. She spent a long time living with her parents, and felt it was difficult to eventually get the confidence to move out alone, but was glad she did. Violet feels that one of the key things about life now is that she can identify with people who are in trouble. She has always had empathy for others, but now experiences it as though it would be happening to her. Because of this, she is interested in other people’s wellbeing, and often gives to charity, and supports her family in various ways.

Violet feels that before her experience of psychosis, she “blundered about”, without much understanding of her feelings, or of other people’s, whereas now she is more in touch with her own feelings, and understands how communication works, and so feels her relationships have improved because of this. She is also appreciative of relationships, and is particularly appreciative of her father, who care for her for so long. She feels she is also

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working hard on her relationship with herself, and understanding herself and her mental health.

Violet still experiences some physical problems as a result of her suicide attempt, and has to take care of herself, however she is immensely grateful for her physical health, and the ability to do physical exercise.

Violet also prioritises caring for her mental health; she reads books in this area, goes on courses, such as a building resilience course, looks on the internet, and talks to her psychologist. She does struggle at times with anxiety, or worrying about other people's opinions of her, but works hard at talking these worries out, rather than letting them build. She is also grateful that she is able to work, as she finds this very normalising.

Afterword - Looking Forward

Violet plans to continue to learn more about caring for her mental health, for instance, by building mindfulness practice into her daily life. She is hoping to take up some volunteering, possibly supporting older people. Violet chose to take part in the research because she finds it important to give back. She feels it is important to share that although she has had difficult experiences, she has been lucky enough to have good ones as well, and wants to give other people the hope that they can recover too.

Albert's Story Summary

Dramatis personæ (in order of appearance in interview)

- Albert - main character. His story is described below
- Parents - Albert's mum and dad. They are supportive of Albert and were worried when he was unwell, especially as he was living in another country. They encouraged him to come home to "get things sorted".
- Girlfriend - Albert was dating his girlfriend when he first started experiencing psychosis. She was very supportive of him, and he ended up living with her in her parents' house. They were also supportive of him, and often took him to doctor's appointments.
- Psychologist - Albert met his psychologist last year in hospital. Albert feels that the psychologist was fantastic, and turned him into a completely new person. He supported Albert to accept his voices, and work with them, and also suggested Albert attend a local Hearing Voices group.
- *The Mad Scientist - one of the voices that Albert hears. He is supportive of Albert, and will give him suggestions and ideas when Albert is stuck with something. The Mad Scientist is very outgoing and tries to support Albert when he tries something new. Sometimes he gets Albert to take on too much, so that Albert eventually crashes, but Albert has now figured out how to handle him at these times. The Mad Scientist also gives Albert confidence.
- *Spanky the Dog - this is another voice that Albert hears. He typically just wants to go out for walks. He can talk in English, but when he does not get his own way, he barks, which can be annoying for Albert.
- *Sparky - another voice that Albert hears. He knows a lot about Albert, because he is Albert when he was a 5 year old.
- Brother - Albert's brother. He was slightly distant when Albert was not doing very well, for instance, he did not come to visit Albert in hospital. Albert wonders if this was because he did not like to see Albert's self harm injuries. Albert also feels he annoyed his brother at one point; sending lots of texts asking if he was safe. Albert and his brother get on better now that Albert is doing well. He feels they were always close, but now they talk more and their relationship seems different.

*Albert also hears negative voices, but he did not describe them in detail during the interview.

Preface – A Time of Difference

Albert first noticed something was different in 2009. He was working as a chef at this time, and found he began talking to the kitchen equipment, and it started talking back. At first he thought it was his imagination, but it kept getting more real, until one day he began hearing voices that did not come from the equipment. One voice was quite nice, and friendly, but the other one was very scary, telling Albert to harm himself, or it would kill him, or members of

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his family. Albert felt that the only way to manage this voice was to do what it said, and he started self harming.

Chapter 1 - The Crisis: lost connections

Albert was living in England at this time, and with the support of his girlfriend and her parents, he tried to access services for help. However, he was told there was nothing wrong. His parents urged him to come home to his native country, where they could support him, and when he did return, he was put in hospital. At the time, although he was not sure what to expect from hospital, he felt that it was the safest place to be, as there was someone available to support him 24 hours a day.

When Albert came out of hospital, he received regular support, had managed to stop self harming, and was starting to feel better. However, he struggled to keep this going, and occasionally slipped back into self harming and feeling bad. During this time he attempted to return to work, and tried to move to England a couple of times, but usually ended up struggling again. In addition, Albert was taking an antipsychotic during this time which had severe side effects, particularly a feeling over overwhelming tiredness.

Chapter 2 - The Shift: acceptance and connections

Albert was living in England when he experienced his most recent breakdown, and went into hospital. On this occasion, his medication was changed, leaving him a completely different person, with high levels of energy and motivation. While in hospital, Albert also began seeing a psychologist, who was very supportive. He helped Albert learn how to accept his voices and stop fighting them, which made life much easier for Albert. He also helped Albert to find the Hearing Voices Network, and Albert began attending meetings.

Chapter 3 - Life Now is Bittersweet

Albert feels that he is still essentially the same person he was before psychosis, but that every now and then he goes through a bad time. There are some downsides to life now, for

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instance, he is no longer able to work the long hours he used to. This, in part, has led to a hard choice to no longer work as a chef, and to do something different with his life.

However, he has now decided to move into peer support, returning to the hospital where he was a patient. He finds this work very motivating, and feels it will suit him, as it is not long hours. He would also like to start a cooking club, and combine his enjoyment of cooking and his desire to help.

Albert feels he has always been a caring person, and believes it is important to help others, however, he has not always had the confidence to try this. He now feels more confident, largely due to the support of The Mad Scientist. Albert also feels he has become nicer, and more patient, and that he understands the problems other people might experience because he has had his own problems.

Albert has also learned more about what he has been through, from attending the hearing voices group, and feels he understands a lot more about his voices, and about himself. He also uses this group, and others that he attends, to pick up tips to help other people.

Albert feels his relationships have changed, particularly with his brother, who he now feels closer to. Albert is also making new friends. Previously when he met a new person, he would not engage with them, but now he will talk to people and make new friends, like at the Hearing Voices group. Albert also feels he has a different relationship with his voices, and feels that if they went away not it would be quite sad. They have kept him company for five years, and to lose them now would leave him feeling lonely, and missing the support of the good voices.

Afterword - Looking Forward

Albert has found he is less impulsive than he used to be, and tries to think before he acts. He feels he has a lot of different possibilities ahead of him now, but is taking time to think things through rather than jumping into something. He would like to go to university and take up

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studying, but wants to wait until he is sure he can manage this. He finds that while before his life was “cook, cook, cook”, he is now focusing on all sorts of different things, such as outside life, work, and helping people.

Nathan's Summary Story

Dramatis personæ (in order of appearance in interview)

- Nathan - main character. His story is described below
- Angela - Nathan's partner. She has supported Nathan through his experience of psychosis. She has talked with him, moved house with him when he was feeling paranoid, helped him to access services, and when he was at his most distressed, fed him and kept him safe.
- Services - Nathan had a negative experience with NHS services. At his first contact, he was asked why he did not just get a job. He received input from a crisis team, but experienced the 15 different people who came to the house as coming to see a "performing monkey" tell his story. Nathan was quite rude to staff at this time, and this led to them withholding medication.
- Soteria Network - Nathan received support from the Soteria Network. At the time, he was sure that there was a conspiracy against him, and often accused staff of trying to poison him, or trying to kidnap him. However, they continued to stay with Nathan and support him, which gave him the space to realise that people are actually caring, and not out to hurt him.

Preface – A Time of Difference

Nathan had been working on a mental health ward, and although it was demanding, he enjoyed it. He then had a fall in the local swimming baths, dislocating his shoulder and hitting his head very hard. He had a few weeks off work, but when he returned, found that he was hypersensitive to situations. For instance, when people on the ward became angry or upset, Nathan would have to walk away. He describes it as having his defences shattered. He eventually left this job and took up a new one as a taxi driver, but found that he was starting to feel quite paranoid. He would draw the curtains when at home, worried that people were watching him, and noticed that he no longer felt right in society. Angela also reported that he was experiencing mood swings at this time. Nathan would spend hours reading things on the internet, around the Mayan calendar, and spiritual ideas. He would follow these ideas, making links in his mind, until he started to lose track of reality. The spiritual ideas that Nathan had been having culminated in him waking up one morning and feeling the spirit of his father above his bed. Nathan found this an emotional experience, and

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told his family, who believes this was an expression of grief, as Nathan's father had recently passed away.

Nathan's paranoia continued, until he and his partner left their home and began to move around the country, as Nathan no longer felt safe anywhere. One evening he and his partner were in bed, and an image came to mind. He had experienced this image many times before, but on this occasion, it slowly disappeared. As it disappeared, Nathan came to the realisation of "oh no, I've been ill".

Chapter 1 - The Crisis: lost connections

Up to this moment, Nathan had believed he was on a spiritual journey, and realising that this was not the case dropped him into a state of terror and panic. Nathan spent the night in this state of terror, resisting the urge to kill himself to make it stop. In the morning, he asked Angela to take him to the mental health services, which she did. Nathan remembers having to ask for help more than once, until he received input from a crisis team. Fifteen different members of the team came to see Nathan, and he began to feel like a performing monkey, as he told his story and beliefs again and again. Often staff would comment on how far away Nathan's family was, causing him further stress. Nathan was also put on various medications, which caused horrible side effects. At one point, after Nathan was rude to staff, they began withholding medication, causing Nathan's psychiatrist to get involved to ensure he received it. Eventually, Nathan chose to discharge himself and attempted to cut out all medication. This caused a severe and painful reaction, which meant he had to reintroduce some of the medication. Over the next few months, Nathan continued to experience distress and paranoia, and he and Angela moved several times to try to cope with this. Eventually, they lived for some time in an upgraded van, driving around the country to wherever Nathan felt safer, albeit temporarily. Nathan's memories of some of this time period are hazy, but he recalls with clarity tying a plastic bag over his head, and tying his hands behind his back, in

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an attempt to end his life. He believed at first that he was doing a deal with God, but as he lay there, unable to breathe, the thought came to him that perhaps it was a game by Lucifer, and he was able to manoeuvre his hands and rip open the bag. At this point, Angela found him, and they agreed it was time to get help again.

Chapter 2 - The Shift: acceptance and connections

Nathan spent some time receiving mindful companionship from the Soteria Network.

Through this time, he began to question some of his paranoid ideas, as he realised that people were caring for him, rather than trying to hurt him. He felt that it was this care which brought him back round, and helped him to trust again.

Chapter 3 - Life Now is Bittersweet

Life now is not always easy for Nathan. He still experiences feelings of paranoia, and also hears voices which can be confusing and frightening, and can prevent him from sleeping.

However, he still loves life, and feels he has learnt a lot about himself, and about how the brain functions. He feels he has a new respect for the brain, and for the mind, and the journeys the mind can take you on. Although sometimes he finds thoughts can be upsetting, Nathan feels he accepts unpleasant thoughts now, and views them as part of being human.

Nathan feels that he is stronger than before, feeling that he has survived the worst of experiences. He also feels that these experiences have led to a shift in his spiritual beliefs, in that he feels life has more meaning to it than he previously realised.

Nathan has realised that people, at their core, are altruistic, and that it is important to care about other people, which he does by supporting them. Some of Nathan's friends and family were not always supportive through his psychosis, but he has made new friends now, and he sees these friendships as more powerful. He attends a Hearing Voices group, where the members empathise with one another, and support each other. Most importantly for Nathan, they do not judge him when he describes an experience, as often they have had

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similar experiences. He feels that because of the support of this group, he no longer has to hide from society. He describes feeling amazing when he walks away from the group.

Although right now Nathan is not ready to work, he is using his time to support people in the new circles in which he has found himself. Previously, he would see his life as consisting of Nathan and Angela, but now he sees life as inclusive, feeling he has become less selfish and more holistically motivated and connected to the rest of humanity.

Afterword - Looking Forward

Nathan is aware that due to some of his experiences, his future now looks very different. He feels he will probably not have children now, as it would not feel fair to bring them into his current situation. He feels he has to accept this, even though he does not feel ok with it. However, Nathan also feels that although things have been difficult, and there will be more struggles in the future, he has hope for the future, and feels he is strong enough to cope with whatever comes.

Carl's Summary Story

Dramatis personæ (in order of appearance in interview)

- Carl - main character. His story is described below
- Wife - Carl's wife. She struggled to support Carl through his psychosis and eventually asked him to leave.
- Psychologist friend - Carl met this friend through attending a Hearing Voices group. He has helped Carl to get to know his voices, and provides support to Carl when he needs it.
- Son - Carl's son. Carl feels his son has "got to grips" with his psychosis and is very supportive. He spends time with Carl, and works hard to understand him.
- Dell - one of the voices that Carl hears. Carl sometimes will also "switch" to Dell. Dell is aged somewhere between 16 and 20, and loves to party. Sometimes he can get Carl to do "silly" things, especially when Carl has had a drink. Carl usually gets on well with Dell.
- Max - this is another voice that Carl hears, and also sometimes "switches" into. Max is protective of Carl. At first he and Carl had a difficult relationship, because Carl would try to ignore Max, making him angry and aggressive. Now Carl uses Max for support, especially in situations where he needs to be assertive.
- Penelope - another voice that Carl hears, and also sometimes "switches" into. Penelope describes herself as a petite blonde lady, and at first she did not get on with Carl, because he does not look the way she thinks she should, and she is a bit more "upmarket" than Carl. Penelope can be quite eccentric at times, and can complicate Carl's life, for instance, he prefers to drink lager, while she likes gin and tonic. But Carl appreciates that Penelope may also be trying to help him, for instance by getting him to eat healthily, and to have better manners.
- Singing lady - another voice that Carl hears. She tends to sing songs that loosely relate to what Carl is doing. This can be annoying, especially as she sometimes picks songs that Carl does not like.
- Crying lady - another voice that Carl hears. She cries when things are not quite right for him. He thinks of her as an alarm system, and when he hears her, will take time to reflect on what is happening for him.
- Harry - another voice that Carl hears. He appears to reflect a younger, boyhood version of Carl, and often says things to Carl that bullies said to Carl when he was at school. Harry often blames Carl for not protecting him from this, and often sides with Max when they feel that Carl needs to stand up for himself.
- Harriet - another voice that Carl hears. She often appears to pick up on Harry's comments and expresses her distress in confusion, for instance, asking why Carl is doing something, or where he is going.
- Commentators - Carl also has two commentators, a male and a female. He is still playing with names for them. They commentate on what Carl is doing all the time (including during the interview) and, understandably, Carl finds this very annoying. Max also finds them annoying and will often tell them to shut up.

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*Carl moves between different parts of his personality. He calls it “switching” but knows that other people call it “dissociation”.

Preface – A Time of Difference

In 2009, Carl began to hear whispering. At first he thought it was his family, and became paranoid, accusing his family of conspiring against him. Over time, the whispering became clearer and he could hear it even when his family were asleep. It reached a point where the voices were clearly audible, and as if he was overhearing conversations.

Carl came up with various explanations for the voices, including ghosts and a government conspiracy. He did look things up online, and learnt about psychosis at this point. However, he felt that he did not want to admit to this, because he worried that he would end up being locked up.

Chapter 1 - The Crisis: lost connections

Carl began to self medicate, with alcohol. During this time, Carl felt scared and overwhelmed, and there were stresses and problems in his relationships with his wife and children. Eventually, Carl had to leave the family home and move into a flat on his own. He saw psychiatrists a couple of times, but did not find this helpful. The first felt that Carl’s problems were down to his drinking, although Carl tried to explain that he was drinking because he was hearing voices. The next psychiatrist that he saw prescribed an antipsychotic. These helped to stabilise Carl’s mood, as he was drifting from hyper to extreme depression, however, he was still struggling with the voices. Carl describes this time as “dark days” and at one point attempted suicide.

Chapter 2 - The Shift: acceptance and connections

Carl began to see a counsellor, and was able to tell him about hearing voices. The counsellor suggested that he attend a Hearing Voices group, where Carl found others who understood his experiences, and that he understood theirs. Carl received empathy from the group, and

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felt normal there. Carl also became friends with the psychologist who facilitated the group and who supported Carl to get to know the different voices he was hearing. During this time, Carl made new relationships in the group, and his relationship with his voices developed.

Chapter 3 - Life Now is Bittersweet

Carl is clear that life right now is not perfect, and still has a lot of downsides. He struggles to sleep, and finds it hard to make new friends, as he struggles to trust new people. He can no longer cook or drive, in case he switches into one of the other voices.

However, there are other aspects to his life now that Carl sees as positive. He describes building relationships with his voices, and using them for support and understanding. For instance Carl will use Max's support to stand up for himself, choose a healthier meal because of Penelope's influence, or take time to reflect when he hears The Crying Lady.

Carl feels he can truly empathise with people now, and understand their pain better. He feels that knowing the different parts of himself have helped with relationships, in that he better understands other people's different wants or needs. Carl's confidence has grown, and he uses this confidence to support others, for instance, he now co-facilitates the Hearing Voices group that he attends. Carl is very supportive of people, and feels it is his way of putting back, as he currently does not work.

Carl also feels that he is stronger than before, as he is able to continue living his life despite hearing so many voices.

Afterword - Looking Forward

Carl hopes to continue to learn about the different parts of himself, and understand what each part is trying to say. He is not well enough to work, but channels his energy and caring nature into helping others, which brings him satisfaction. Alongside continuing to co-facilitate the Hearing Voices group that he attends, he is looking to start one in another city.

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He is also trying to build up the confidence of other group members by asking them to facilitate at times.

Carl took part in the research because he thinks it could be helpful for other people who are going through similar experiences, to know that there is light at the end of the tunnel. He also hopes it will bring awareness that people with psychosis are not monsters, they're just people who struggle with what life has dished them out, and that all experience is genuine experience, even though it might not be something others can see or hear.

Bradley's Summary Story

Dramatis personæ (in order of appearance in interview)

Bradley -	main character. His story is described below
Mum and Dad -	Bradley lives with his mum and dad and they have always been very supportive of him. They visited daily while he was in hospital and now provide space to talk about his experiences.
Early Intervention -	Bradley received support from an Early Intervention service for three years following his time in hospital, and describes them as fantastic. He saw them weekly, and spent time talking and offloading, as well as participating in activities such as bowls.
Voice -	Bradley hears a female voice, which he did not name in the interview. Bradley used to see her as a woman who just swore and put him down, but now sees her as a sensitive soul, who may swear if she is frightened or unsure. When this happens, Bradley talks to her and tries to work out what is happening for her. Sometimes she apologises during these discussions. Sometimes the voices can offer Bradley support when he needs it.
Counsellor -	Bradley saw a counsellor to talk through his experience of rape. The counsellor was very supportive, and gave Bradley time to talk, share his worries, and offload them.

Preface – A Time of Difference

In 2004, Bradley attended a wedding where he drank heavily. When he woke up the next day, he believed he had been raped. He accused a family member, however the police investigated and reported back to Bradley that the incident had not actually occurred.

Bradley understandably felt considerable pain and distress following this incident, which was exacerbated by the statement of the police that it had not actually happened.

For the next two to three years, Bradley managed to continue with his life, but in 2006, he began to hear voices and hallucinate. He felt his boss was asking too much of him, and so resigned from his job.

Chapter 1 - The Crisis: lost connections

After Bradley left his job, he began walking the streets of his home town. He would leave the house at around 5.00 a.m., and would not return until around 12.00 a.m., walking around 10 miles each day. If he saw anyone he knew, he would avoid them. Bradley was hallucinating

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constantly at this point. Many of his hallucinations were like horror films, for instance, he thought he was going through the trials depicted in the “Saw” film franchise. He also believed he was involved in a game, and had won £3.5 billion. In 2007, Bradley collapsed, and agreed to go into psychiatric hospital.

Chapter 2 - The Shift: acceptance and connections

Although Bradley found hospital frightening at first, over time, he got to know people, and found they had been through similar struggles to himself. He found that they were able to support each other. Prior to coming into hospital, Bradley felt he had lost his trust for the world, including his parents, who he had pushed away. However, his parents visited every day while in hospital, and through this, he regained his love and trust for them. At this point, Early Intervention became involved and supported Bradley for three or four years. They gave him space to talk about his experiences, and helped him to rationalise his thoughts, and the hallucinations he was still experiencing. He was also able to talk about his experience in 2004, and with time began to understand that it had also been a hallucination. He slowly began to come to terms with what that meant for him. Bradley also attended a Hearing Voices group, and found that it is important to normalise the experiences he was having and make them part of his life.

Chapter 3 - Life Now is Bittersweet

Bradley feels that if his episode of psychosis hadn't happened, he would not be doing what he is doing now, and feels that life has changed for the better. Bradley spends a lot of time volunteering for different organisations. Over time, he has volunteered for around 15 organisations, including working in conservation, working with young people, working with people with learning difficulties and disabilities, delivering mental wellbeing training, and facilitating a Hearing Voices group, which he established in his local town. This last the sees

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as important because it is his way of offering hope to people, and also sees it as a way of giving something back.

Bradley feels he has a wide variety of opportunities available to him, and thinks that his confidence and independence have grown following these experiences, because he had to build himself back up after hitting rock bottom. Bradley has always had a caring side, but when he was younger did not have the confidence to pursue this. Due to this shift in confidence and independence, Bradley has been able to take on new learning opportunities. He has completed his Level one in British Sign Language and is also currently part way through a diploma in education. He also undertook part of a counselling course, and is hoping to go back and compete that in the future.

Bradley feels that his relationships have improved, and he particularly values his mum and dad. He talks to them often about his experiences, and feels they are very supportive. Bradley's relationship with his voice has also improved; he talks to her, and reflects on what she says and how that might relate to how he is feeling. He also uses the counselling skills he has learnt to try to understand himself and his voice.

Bradley has found that prayer became very important to him during his experiences before going into hospital. He still prays now, both for himself, and for others.

Afterword - Looking Forward

When thinking about the future, Bradley tries to take on day at a time and not rush things. He'd like a part time job one day, but is happy to wait until he is ready for that. In the meantime, he plans to continue volunteering, and is in the process of becoming a peer support worker for people struggling with mental health. Bradley also plans to join a signing choir, to develop his sign language in order to take his Level Two in British Sign Language. He also plans to go abroad on holiday this year, for the first time since experiencing psychosis.

Posttraumatic growth following psychosis

Bradley took part in this research in order to show people that those who have experienced psychosis are just normal people. He feels there are lots of negative stereotypes around of people with mental illness as dangerous and he would like to challenge that. He hopes people will learn a lot from this research.

Sarah's Summary Story

Dramatis personæ (in order of appearance in interview)

- Sarah - main character. Her story is described below
- Mom - Sarah had a tumultuous relationship with her mother growing up, and at times her mother could be very detached. However, when Sarah was feeling suicidal, and services were not listening, her mom came with her to the G.P. and told them that they needed to listen to Sarah and take her seriously. Once Sarah became more comfortable in her experiences, she became able to talk about them with her mom, and they can laugh and joke about them now.
- Early Intervention Team - Sarah was referred to an Early Intervention service after being in hospital. They did not get along. She stopped taking her medication, and they wanted her to go back onto it. They were only able to offer her a Cognitive Behavioural Therapy group, which she attended, but did not find helpful.
- Physiotherapist - Sarah saw a physiotherapist for five years. He was linked to mental health services, and worked a lot with Sarah on physical boundaries, safety, centring and grounding. They worked on a mix of exercises and massages, and eventually Sarah began resistance training. The physiotherapy helped her to feel less fragmented in herself, and also helped her to see that she had been living in a state of high anxiety, without realising it.
- Hearing Voices group - Sarah began attending a Hearing Voices group and appreciated her experiences being normalised. Prior to this, she had felt quite alone with her experiences, and had received the message from services that the experiences were something to be feared, or resisted. Sarah found that in the Hearing Voices work, she was able to feel ok to hear voices, but also found that she was able to put words to her experiences, and process them in a different way.
- Voices/Beings - Sarah hears more than one voice, but did not name them during the interview. She feels they are more than “voices” as she can sense their presence, so prefers to call them beings. Over time she has found that she can ask them for support when she needs it, or can discuss ideas with them, and use them for inspiration. She finds it challenging at times, because she likes to be quite rational, while the beings are not always rational, but she feels that through talking with them she has learnt to be accepting that there may be more than one idea of truth or reality. She has also used her relationship with one being, that has been constantly positive through her life, to build relationships with other people, using the feelings she gets from the relationship with the voice as a sort of measurement for her relationships with others.

Preface – A Time of Difference

Sarah grew up in mainland Europe, where most of her experiences happened. She has heard voices all her life. When she was around 10 or 11, she began to feel as if something was different about her. Before this, she had assumed that everyone heard voices, but as she

Posttraumatic growth following psychosis

realised that this was not the case, began to feel more anxiety and distress. The voices that she heard began to be more critical and more problematic, and she began to feel as if there were bad things in the room, or outside the windows trying to get to her. Sarah also began to experience suicidal impulses.

Chapter 1 - The Crisis: lost connections

She lived with these experiences until she was about 15 or 16, when she had what she calls her first experience of psychosis, which was an overwhelming experience of powerful emotional states where her experience of herself became fragmented. These could affect her physically, so she ended up having what she calls adult tantrums. She tried to control these states, by numbing herself and trying to not feel her emotions by constantly having her attention elsewhere. When she did then return to her emotions and body, it would be very scary, chaotic and overwhelming for her. When Sarah was 22, she began to think that life should not be this difficult, and reached out to mental health services for help. Initially she struggled to be taken seriously as she was seen as being quite high functioning. She found this frustrating, wondering how she should look and behave for others to believe that she is suffering. Eventually, Sarah's mom intervened, and convinced services that Sarah was genuinely feeling suicidal. She was admitted to hospital for a month, and then received support from an Early Intervention team. Sarah did not find this service helpful, as she felt that the medication that was prescribed turned her into a zombie. She did not want to take medication unless she could do so in hospital where she would be thoroughly monitored, and as the service did not want to admit her, that was the end of her involvement with that team.

Chapter 2 - The Shift: acceptance and connections

At this point, Sarah had begun to receive physiotherapy. This was associated with mental health services, and she accessed it for five years. She worked with her physiotherapist on becoming less fragmented in herself. She feels it was the work she did with the

Posttraumatic growth following psychosis

physiotherapist that allowed her to feel ready to connect with the Hearing Voices Network. In the city she was living in at the time, the network offered groups facilitated by workers, informal talking sessions, and different courses. Before attending the Hearing Voices groups, Sarah had had to rely on her own framework and understanding of her experiences, which made sense of them, but left her feeling quite alone. This was exacerbated by her time with services, where the message was that she had to get rid of her voices. The groups allowed her to learn that it was ok to talk about these experiences, and that it was ok to have them. She felt acceptance from the group that the voices were part of her identity and part of her experience. She also found it helpful to be able to put words to her experiences, as this made them less overwhelming, and helped her to process them.

Chapter 3 - Life Now is Bittersweet

Sarah now sees her experiences as a wealth of inspiration. She sees them as useful, for instance, if she gives a talk about her experiences, she will invite some of the beings to come and support her. She finds that when she does this, she can feel them near her, giving off a warm, comforting energy, and describes it as similar to asking a friend along for support.

Sarah feels that her engagement with the beings now is very similar to friendships. She will have conversations with them, and they will give her different ideas. Sometimes they say things that do not resonate with her own beliefs, and she finds this challenging, but in a good way. She finds that they are also very good at coming up with creative ideas, when Sarah is writing or painting. At times they can give off a strong sense of excitement, leaving Sarah feeling a bit wired, and she has to be careful at these times.

Sarah finds that these experiences leave her with a strong sense of connection, both to herself, and to the world around her. She feels that the world comes alive in a different way because of this, and feels a sense of awe and humility, and she finds that this experience guides her in making ethical choices.

Posttraumatic growth following psychosis

Sarah finds it hard to imagine life without these experiences, but does feel that some things would have been easier. For instance, she finds that if she goes against her values, then the beings will let her know that this is not ok, which makes it hard sometimes to always live by expected norms and values of society, for instance, no spontaneous dancing in the streets. Sarah has also thought about a career as a psychiatrist, but feels that this would be unlikely to happen as she would end up risking her health.

Similarly, Sarah has to be careful about how she connects to others. She finds that she can often build very strong, deep, meaningful connections with others, but that this can also be quite scary for her. She does, however, feel that these connections have resulted in positive relationships. She often uses the relationship she has with one of the beings as a sort of template for other relationships in life, and feels that a lot of her skills in how to be in a relationship have come from her relationship with the beings.

Afterword - Looking Forward

Sarah feels that she has not yet fully been able to make use of the resources available to her in the form of the beings. She has a sense that there is more there for her to draw on and hopes to be able to make use of it one day. She also wonders if these experiences could be a source of energy for her, as well as being a source of inspiration and support.

Appendix 2-B

Notes for contributors to *Psychosis*

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Section Three: Critical Appraisal

Critical Appraisal

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Critical Appraisal

This thesis explored relationships between distressing mental health experiences and trauma, and the possible relationships between that trauma and posttraumatic growth (PTG). The literature review aimed to explore what elements of mental health inpatient support could be considered to be traumatic. A framework was developed which incorporated current understandings of trauma, and was used to interrogate qualitative studies investigating experiences of inpatient care. The review showed that throughout the process of hospitalisation, from being admitted, through being on the ward, to the experiences following discharge, people endure a wide range of experiences that could be considered to be traumatic, and will often undergo multiple experiences, compounding the trauma.

Following the literature review, the research paper aimed to learn if the PTG that can be experienced following psychosis remained stable over time, and how it felt to experience that growth. Narrative analysis was used to investigate participants' stories of psychosis they felt had been traumatic, and how those experiences led to growth and transformation. Although participants moved around in time while telling their stories, a clear structure of the stages that individuals moved through emerged during analysis; Preface – A Time of Difference; Chapter 1 – The Crisis: Lost Connections; Chapter 2 – Acceptance and Connections; Chapter 3 – Life Now has Transformed; and the Epilogue – Looking Forward. The characters who had supported individuals to reach PTG were also apparent.

The appraisal below will describe how my personal understanding of unusual experiences, or psychosis, has changed over time, what influenced me to investigate the connection between psychosis and posttraumatic growth (PTG), and how this investigation further influenced my way of thinking.

Introduction to psychosis

One of my first posts in mental health was working in an Early Intervention in Psychosis (EIP) Service, and it was in this job that I first learnt about psychosis, and about the standard approach to intervention that is taken in the United Kingdom (UK). This service, as is standard in EIP services, took a bio-psychosocial approach (Read, Bentall & Fosse, 2009). This meant that although the service did not take a wholly medical perspective, there was still a shared assumption that psychosis and schizophrenia were due to disturbances in the brain, and that medication was therefore necessary for a person to recover from psychosis. This assumption was made apparent in various ways, for instance in meetings staff would remark that a client had stopped taking medication because they were feeling better; to which another member of staff would invariably reply that of course they felt better, they had been taking medication! As I had no previous understanding of psychosis, or any personal experience, I accepted the dominant narrative in the team, and felt that the biological explanation made sense.

In addition to medication, the service had an emphasis on social interventions, and psychological support, including developing psychological formulations for clients. However, although the team psychologist would often suggest formulations, or try to remind the team of this option in meetings, it was only taken up sporadically. On reflection now, the bio-psychosocial model that the service followed had in fact become “the bio-bio-bio” model (Read, et al., 2009). The biological aspect was always the most important part, and we could only incorporate the psychological or social support once we had the biological aspect, the medication, in place.

While working in this service, I could see the very positive work that happened, and did see many clients helped, both by medication, and by the social support and psychological interventions they may have received reinforcing my acceptance that this way of working

was beneficial. However, I still felt confusion around the diagnosis of schizophrenia, and the label of psychosis. My understanding was that typically an individual would need to experience the “symptoms” associated with the label psychosis for at least 6 months before the diagnosis of schizophrenia could be made (American Psychiatric Association [APA], 2013). However, this distinction seemed arbitrary to me, and I struggled to think of a comparable example in physical health, where a certain length of time is the difference between an experience and a diagnosable medical condition. However, other members of staff did not appear to echo my confusion, so I assumed my uncertainty around this was due to my lack of knowledge in the area, and that it would become clearer the more time I spent working in this area, and the more training I received.

Clinical Psychology Training

During training, I learnt that my uncertainties with regard to diagnosis are not completely unusual. In fact, I was frequently encouraged to question previously held ideas, to question the way in which mental health services are structured, to question the very concept of mental “health” – in short, to question everything. I began to feel more comfortable with uncertainty, and with learning to hold ideas lightly. As I attended teaching, and spent time on different placements in different services, I began to think more about the purpose of diagnosis in relation to mental health.

My main interest was still in the area of psychosis, and I began to learn more about the origins of this label, and the origins of the diagnosis of schizophrenia. Kraepelin was one of the most well-known names in this area, after he labelled a certain type of mental illness that began in adolescence and continued into inevitable decline as “dementia praecox” (Boyle, 1990). He used a circular logic that some have argued has continued to underpin the diagnosis of schizophrenia; declaring that it is not possible to recover from dementia praecox, and when people with this diagnosis did recover, stating they must have been misdiagnosed

(Read, 2013). Bleuler, who coined the term schizophrenia, rejected the prognostic element of Kraepelin's dementia praecox (Maatz, Hoff & Angst, 2015). Unlike Kraepelin, Bleuler noted the importance of understanding an individual's experience of schizophrenia (Maatz, et al., 2015), however, he was unable to establish the physical causes that he sought, nor was he able to establish a predictable course for his newly named category of mental illness (Read, 2013). As I learnt more about the history of schizophrenia, I began to see that a diagnostic category I had previously accepted as a valid scientific concept was in fact based on poor science.

At this time, I began to learn about the methods of categorising mental health diagnoses in general, and also about the current ways of categorising schizophrenia. Diagnosis in mental health is typically problematic (Jablensky, 2016). There are problems with how reliable a diagnosis is (as in whether two clinicians can reliably give the same diagnosis to a person), and also with the boundaries of diagnosis (Paris, 2013); at what point an experience becomes a "clinically significant symptom". These problems are evident with regards to schizophrenia, for instance, in the revised fourth edition of the Diagnostic and Statistical Manual (DSM), (APA, 2000), a person had to experience two out of five "symptoms" (delusions, hallucinations, disorganized speech, disorganised or catatonic behaviour and negative symptoms) to receive a diagnosis. This meant that there were 15 different ways in which a person could have schizophrenia, with no overlap between them (Read, 2013). The most recent edition of the DSM has retained the "two out of five" rule, however, one of those must be one of the first three in the list (delusions, hallucinations or disorganized speech) (APA, 2013). This has narrowed down the ways in which to have schizophrenia to nine. As I read more about this, I felt that it showed that the category of schizophrenia was simply meaningless in scientific terms.

In my second year of training, I heard John Read talk about the traumagenic model (Read, Perry, Moskowitz & Connolly, 2001), and spent time reading around this. The idea that experiences associated with psychosis and schizophrenia are in fact a response to early traumatic experiences is one that resonated with me. I began to feel that perhaps my own understanding of psychosis, or unusual experiences, was that they are a completely normal response to abnormal situations. At around the same time, I read around the idea that psychosis is simply on a continuum (van Os, Hanssen, Bijl & Ravelli, 2000); that we all have had experiences such as hearing the phone ring when it has not, or hearing your name called on the street, but no one else hears it. This idea also resonated with me, and at this point, there was a shift in my understanding of unusual experiences. I had moved from seeing them as categorisable and diagnosable experiences that should be reduced or stopped completely, to seeing them as normal responses to abnormal situations, which we should spend time trying to understand.

The research idea

I had begun to feel that focusing on the negative consequences of psychosis, and thinking of psychosis as an “illness” with “symptoms” was not the only, or the most beneficial, way of thinking. This was supported by reading that I had done in my first year around recovery from psychosis, and the findings of many research studies that suggested that recovery from psychosis appeared to include elements of growth (Pitt, Kilbride, Nothard, Welford & Morrison, 2007). I began to wonder if there was more to this idea of growth, and whether growth was more than just an element of recovery, but was actually a phenomenon in its own right.

This led me to reading and thinking about the theory of PTG (Tedeschi & Calhoun, 2004). Although there are other theories around growth following trauma, the concept of PTG appealed to me, because the theory acknowledges that distress can coexist with growth.

Intuitively, I felt that this made sense for me, based on the clients I had known through Early Intervention; many would still experience distress from their experiences of psychosis, but often talked about positive aspects from them as well. Furthermore, I felt that the theory of the process underlying PTG would be applicable with regards to psychosis; a trauma challenges a person's way of understanding the world, as does psychosis, and growth comes from their attempts to develop new understandings, which occurs following an experience of psychosis.

As I carried out background reading for the project, and entered my third year placement in an Early Intervention service, I learnt about alternative ways of supporting people with psychosis, such as Open Dialogue approaches (Seikkula & Olson, 2003), and The Soteria Network (Mosher, 1999). Learning about these approaches, and about their success led me to further question the approach of the medical model. Much of this questioning left me conflicted, as although I had seen a medical model prove to be unhelpful for some people, I had also seen it prove to be very helpful for others. Additionally at this time, I learnt that recovery rates for psychosis in developed countries are typically poorer than recovery rates in developing countries (Hopper & Wanderling, 2000). This raises the obvious question of what it is that these countries do that developed countries do not, or perhaps, what it is that developed countries do that developing countries do not. For instance, many cultures in developing countries may view an individual who hears or sees things that others do not as special in some way, for instance, sangomas in many parts of southern Africa are seen to have a direct link to their ancestors, and are able to talk with them and hear their guidance (Hund, 2004). Sangomas are viewed with respect, and are often called upon to intercede with the ancestors on people's behalf. Even when not viewed with this high level of respect, often people with unusual experiences are cared for by family, and may be supported to perform low stress, manual jobs (Hopper & Wanderling, 2000). By contrast, in

developed countries, typically there is a lot of stigma associated with mental health, particularly with diagnoses such as schizophrenia (Frances, 2013), people who are deemed “unwell” are placed in hospital, away from family and friends, and their experiences are dulled by the use of antipsychotic medication.

These alternative understandings of unusual experiences resonated with me, as I had grown up in a developing country. Prior to living in the UK, I had lived among people who believed that they could speak to their ancestors, who firmly believed in the power of the evil eye, and who were as likely to seek the advice of a sangoma as they were to seek advice from a medical doctor. Thus it felt that the more I learnt about accepting people’s own explanations for their experiences as valid, and finding ways to make sense of these experiences in whatever way fits for the individual, the more I felt I was returning to an earlier, more intuitive understanding of unusual experiences.

The Research Process

Screening Interviews

With support of my supervisors, I began thinking about the design of the study. Through discussion, we established that in order to clearly see the way in which PTG occurred over the long term following psychosis, it would be important to ensure that we did not interview people who were currently distressed by their experiences. We felt that the best way to do this would be to use the positive subscale of the Positive and Negative Syndrome Scale (PANSS) (Kay, Fiszbein & Opler, 1987), as this has been designed for the purpose of assessing experiences of psychosis. The PANSS can be carried out in a very structured way, however, my supervisors and I felt that it would be best to carry it out as a less formal clinical interview, which had more flexibility, and would allow me to work on building rapport with potential participants. I was aware that this might make the research process more difficult, as participants’ first contact with me would be discussing “symptoms”, however, I felt that it

was important to have a clinical tool to guide decisions about whether an individual could or should take part in the study.

However, I had not fully anticipated the power dynamics that would occur due to the use of the PANSS. Although I was aware that there would be a power imbalance between myself as the researcher and my participants, the use of the PANSS shifted this imbalance towards giving me the power. Simply by asking about clinical “symptoms” of psychosis, I felt as if I was presenting myself as a medical professional, whose aim was to assess an individual’s mental health, from an assumed position of “mental wellness”. This was further emphasised when it was apparent that participants were familiar with the PANSS from their time in mental health services.

Additionally, when I was carrying out the PANSS with people who were not currently distressed by their experiences, or whose “symptoms” were not at a clinical level, there was still an obvious power imbalance, one that was perhaps more subtle. Many of the questions I asked were simply no longer relevant to these individuals, and I began to wonder how I would feel, or what I might answer with, if a person was asking me questions such as “do you think you are special in some ways”, or even “do you ever imagine things that are not true?” (Kay, Fiszbein & Opler, 1987). Although the potential participants understood the purpose of this screening, and agreed to it, it still raised questions for me around the power given to the researcher by institutions, and wider culture.

These power dynamics can sometimes be addressed through the use of participatory research. This involves ensuring that the populations about whom research is being carried out have a say in how that research develops (van der Riet & Boettiger, 2009). When first planning the research, I had hoped to, at the very least, seek service users’ advice on the materials I would be using, or preferably involve someone with lived experience of mental health support or psychosis throughout the research. However, although I contacted service

user involvement networks, due to time constraints, I was unable to involve any service users in the project. I obviously cannot know how this may have affected the power imbalance, but it is possible that they may have foreseen some of the elements that shifted the power in my favour, and been able to help me to redress the balance.

Research interviews

I found at the start of interviews, I had to work hard to attempt to redress the power imbalance that had been established during the screening conversations. Many participants expressed concerns that they may not tell their story in the right order, or they may not tell me what I needed to hear. As I had taken a narrative approach to the study, I was aware of the ways in which the interviewer and the interviewee co-construct a story together, and I was hoping to encourage participants to tell their story with as few prompts as possible.

However, as my initial contact with participants had been very structured, and symptom focused, it was apparent that they were expecting the interview to be similarly structured. I therefore had to work hard at creating a rapport, alongside explaining that this interview would be very different to the initial conversations that we had had. Although this may have required more effort than otherwise because of the use of the PANSS, I felt I was able to achieve a good rapport with each participant, as they evidently relaxed into telling their stories to me, feeling able to move around their narratives as different memories occurred to them, and sharing with me some awe-inspiring experiences.

In addition to the power imbalance described above, it was apparent that my position as a trainee clinical psychologist, and therefore an employee of the NHS, was relevant to the way in which some stories were told. For instance, one person had found NHS services to be unhelpful, but before telling me this, stated that I probably did not want to hear that part, alluding to my NHS employment. I was able to clarify with him that I certainly wanted to hear *all* aspects of his experiences, positive or negative, regardless of who I was employed

by, and he shared some of his negative experiences with services. However, I do wonder to what extent he censored his story or altered his language, knowing my affiliation with the NHS, or to what extent other participants did this, without raising it as an issue.

Despite these initial struggles, and my concerns about my affiliation with the NHS, I feel I was able to create a warm, supportive environment, which allowed participants to share their stories with me. During interviews, I found myself in awe of participants' stories, from their descriptions of psychosis and the difficulties they encountered, to their lives now, and how their experiences seemed to enrich them. I was also struck by the enthusiasm so many had for this area of research. I found this particularly inspiring, especially when I hit the inevitable bumps along the road of research. Each of the people I interviewed told incredible stories, and many made it clear that they wanted others to know that although psychosis is a distressing, even traumatic experience, it brings more to life than they could have anticipated.

Reflections

I feel that this journey has broadened my understanding of psychosis, and also helped me to develop a more nuanced understanding than when I first began working in this field. I also feel that there is still more for me to learn, and I hope that does not change. With that in mind, I hope to continue to be able to hold my ideas lightly, both in research, and in clinical work. I have also enjoyed learning about the alternative ways of understanding psychosis, and supporting those who experience it. I am hopeful that these alternatives will gain ground and we will see a further move away from the "bio-bio-bio" model that I first encountered when working in this area.

Most importantly, the research process has taught me the incredible worth of each individual's story. I have learnt more about the enormous value in truly hearing people's experiences, and learning from their explanations of these experiences. This journey has tremendously influenced my clinical work, with regards to both hearing clients' stories of the

Critical Appraisal

distress of psychosis, but also knowing the importance of listening out for the potential for growth. I am immensely grateful to those who took part in this research study who have shared their passion with me; a passion for communicating that as well as being difficult, psychosis can be a transformative experience. I can now hold that passion when it comes to future research, but also when I am working with clients. I felt that Nathan summed the key message up for me when he said; “if you get through it, oh it can make you go wow, just those experiences”.

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Section Four: Ethics

Ethics Section

Natasha Goakes

Doctorate in Clinical Psychology

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Word count: 3433

All correspondence should be sent to:

Ethics

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Final University Research Ethics Committee application form

**Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University**

Application for Amendment to Previously Approved Research

Instructions: Please re-submit your original research ethics approval documents with any amendments highlighted in yellow, attaching this form as a cover sheet.

Completed documentation should be submitted as a single PDF by email and in **signed** hard copy to:

Dr Diane Hopkins
Faculty of Health & Medicine
B03, Furness College
Lancaster University
LA1 4YT
d.hopkins@lancaster.ac.uk

1. Name of applicant: Natasha Goakes
2. E-mail address and phone number of applicant: n.goakes@lancaster.ac.uk 07935838403
3. Title of project: An investigation into the stability of posttraumatic growth following an experience of psychosis
4. Project reference number:RS2015/5
5. Date of original project approval as indicated on the official approval letter (month/year): 08/2015

Amendment request
6. Please outline the requested amendment(s): Have the option of interviewing participants via phone or skype, rather than solely in person.
7. Please explain your reason(s) for requesting the above amendment(s):To widen recruitment from current geographical location (north of England) to the whole of the UK

Signatures

Applicant: Natasha Goakes _____ Date: 22/01/16 _____

Ethics

Project Supervisor: _____ Date: _____

(if applicable)

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

Instructions

1. Apply to the committee by submitting
 - ✓ **The University's Stage 1 Self-Assessment Form (standard form or student form) and the Project Information & Ethics questionnaire.** These are available on the Research Support Office website: [LU Ethics](#). [The Project Information & Ethics questionnaire should be sent directly to Debbie Knight, RSO, Bowland Main.]
 - ✓ **The completed FHMREC application form**
 - ✓ **Your full research proposal (background, literature review, methodology/methods, ethical considerations)**
 - ✓ **All accompanying research materials** such as, but not limited to,
 - 1) Advertising materials (posters, e-mails)
 - 2) Letters of invitation to participate
 - 3) Participant information sheets
 - 4) Consent forms
 - 5) Questionnaires, surveys, demographic sheets
 - 6) Interview schedules, interview question guides, focus group scripts
 - 7) Debriefing sheets, resource lists
2. **Submit all the materials electronically** as a **SINGLE** email attachment in PDF format. Instructions for creating such a document are available on the FHMREC website (<http://www.lancs.ac.uk/shm/research/ethics/>).
3. **Submit one collated and signed paper copy** of the full application materials. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the research ethics committee website <http://www.lancs.ac.uk/shm/research/ethics>. Applications must be submitted by the deadline stated on the website, to:

Diane Hopkins
Faculty of Health & Medicine
B14, Furness College
Lancaster University, LA1 4YG
d.hopkins@lancaster.ac.uk

5. Attend the committee meeting on the day that the application is considered.

1. Title of Project: An investigation into the stability of posttraumatic growth following an experience of psychosis
2. If this is a student project, please indicate what type of project by ticking the relevant box: <input type="checkbox"/> PG Diploma <input type="checkbox"/> Masters dissertation <input type="checkbox"/> MRes <input type="checkbox"/> MSc <input type="checkbox"/> DClinPsy SRP <input type="checkbox"/> PhD Thesis <input type="checkbox"/> PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being <input type="checkbox"/> MD <input checked="" type="checkbox"/> DClinPsy Thesis <input type="checkbox"/> Special Study Module (3 rd year medical student)
3. Type of study ✓ Involves direct involvement by human subjects <input type="checkbox"/> Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

Applicant information
<p>4. Name of applicant/researcher:</p> <p>Natasha Goakes</p>
<p>5. Appointment/position held by applicant and Division within FHM</p> <p>Trainee Clinical Psychologist, Division of Health Research</p>
<p>6. Contact information for applicant:</p> <p>E-mail: n.goakes@lancaster.ac.uk Telephone: 07935838403</p> <p>Address: Furness College, Lancaster University, Lancaster, LA1 4YG</p>
<p>7. Project supervisor(s), if different from applicant:</p> <p>Name(s): Suzanne Hodge, Graeme Reid</p> <p>E-mail(s): s.hodge@lancaster.ac.uk, graeme.reid@lancashirecare.nhs.uk</p>
<p>8. Appointment held by supervisor(s) and institution(s) where based (if applicable):</p> <p>Dr Suzanne Hodge - Lecturer in Health Research, Division of Health Research, Lancaster University</p> <p>Dr Graeme Reid - Consultant Clinical Psychologist/Professional Lead, Step 5 Adult Psychological Services, Central Lancashire, Lancashire Care NHS Foundation Trust, and Honorary Lecturer in Clinical Psychology, Lancaster University</p>
<p>9. Names and appointments of all members of the research team (including degree where applicable)</p> <p>Research team consists of:</p> <p>Lead Researcher - Natasha Goakes (Trainee Clinical Psychologist)</p> <p>Research Supervisor - Suzanne Hodge (Lecturer in Health Research)</p> <p>External Supervisor - Graeme Reid (Consultant Clinical Psychologist/Professional Lead)</p>

The Project
<p>NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.</p>
<p>10. Summary of research protocol in lay terms (maximum length 150 words).</p> <p>Research suggests that psychosis can be considered to be a traumatic experience (e.g. Morrison, Frame and Larkin, 2003), as can associated experiences such as psychiatric hospital admission (e.g. Morrison, Bowe, Nothard and Larkin, 1999). However, research also suggests that recovery from psychosis can involve change and growth in many areas of life. This project will investigate whether recovery from psychosis can involve elements of posttraumatic growth, as described by Tedeschi and Calhoun in 2004.</p>

The project will interview people who have had an experience of psychosis, and who now consider themselves to have experienced elements of posttraumatic growth. If, following the screening process, potential participants are felt by the lead researcher to be too high risk for the study, they will be informed of this fact, and the lead researcher will contact the potential participant's G.P. if necessary. Interviews will be audio recorded and transcribed, and the data will be analysed by narrative analysis.

11. Anticipated project dates

Start date: October 2015 End date: May 2016

12. Please describe the sample of participants to be studied (including number, age, gender):

Participants will be people who have had an experience of psychosis that they consider to have been traumatic, and who now consider themselves to have experienced elements of posttraumatic growth. In the recruitment materials elements of posttraumatic growth will be described as whether "parts of your life are better in some ways than before experiencing psychosis" in order to help potential participants recognise themselves (please see the participant information sheet, Appendix 1).

The ideal number of participants will be between 8 and 12. The minimum number of participants will be 4.

Both male and female participants will be included, from age 18 upwards.

To be included an individual must:

- have the ability to give informed consent
- have had an experience of psychosis, defined as having been assessed as eligible for the First Episode of Psychosis pathway within an early intervention service
- consider some aspect (symptoms, treatment, etc) of their psychosis to be traumatic
- consider themselves to have experienced some aspects of posttraumatic growth, outlined by the participant information sheet

Individuals will be excluded if they:

- present a high current level of risk to self or others, assessed by the lead researcher in a screening assessment.
- are currently experiencing clinically significant psychotic symptoms (assessed by the lead researcher using the positive symptoms subscale of the PANSS (Kay, Fiszbein and Opler, 1987). Although not designed for use over the phone, the positive subscale can be used in this way and will still be a valid measure of assessing symptoms.)
- have had less than 3 years since their first treated episode of psychosis.

If potential participants do not get through the screening because they are experiencing current clinically significant psychotic symptoms, or are a high risk to themselves or others, the lead researcher will share this information with the potential participant's G.P. If potential participants do not get through the screening for other reasons (e.g. not having experienced psychosis or do not feel any part of their experience was traumatic), the lead researcher will inform them in a sensitive manner that they are not suitable for the study.

13. How will participants be recruited and from where? Be as specific as possible.

Participants will be recruited from online forums, support groups and networks relating to psychosis (for example The Hearing Voices Network and The Paranoid Network).

The lead researcher (Natasha Goakes) will contact the moderators of online forums, asking for a message to be placed on an open message board, describing the research, providing contact details and asking that any interested person contact the lead researcher via email or phone if they are interested in taking part (Appendix 2).

The lead researcher will also contact the facilitators of support groups and networks in the nearby area, asking to attend a meeting to describe the research and provide recruitment packs with participant information sheets and contact details. After each attendance, recruitment packs will be left and people will be asked that they contact the lead researcher via email or phone if they are interested in taking part. The researcher will also contact support groups further afield and ask to send through recruitment information to be shared at the next group, if the facilitator feels this is appropriate.

Once participants have expressed an interest in taking part, the lead researcher will briefly screen via phone to check that they fit the inclusion/exclusion criteria (see above). The lead researcher will also take a note of the participant's GP in case the participant is currently experiencing psychotic symptoms, low mood, or is otherwise a risk to themselves or others.

Recruitment will continue until the required number of participants has been reached. If more than the required number of participants express an interest, recruitment will occur on a first come, first served basis. Face to face interviews will be restricted to participants in the north of England, although they will also be offered interviews via phone or Skype. Participants who are based further away will be interviewed via phone or Skype.

If potential participants do not get through the screening because they are experiencing current clinically significant psychotic symptoms, or are a high risk to themselves or others, the lead researcher will inform them sensitively of her concerns, and will share this information with the potential participant's G.P. If potential participants do not get through the screening for other reasons (e.g. not having experienced psychosis or do not feel any part of their experience was traumatic), the lead researcher will inform them in a sensitive manner that they are not suitable for the study.

If potential participants do not meet the inclusion/exclusion criteria, they will be informed of this at the time of the screening assessment, and will also be informed that their contact details will be destroyed. The lead researcher will be responsible for destroying the contact details.

14. What procedure is proposed for obtaining consent?

Once a potential participant has expressed an interest in taking part, the lead researcher will confirm that they meet the inclusion/exclusion criteria. This will be done via phone.

Face to face: The researcher and participant will then agree a convenient time and place for the interview. Prior to conducting the interview, the researcher will read through the consent form with the participant, clarifying any points where necessary and then ask the participant to sign the consent form.

Phone or Skype: Participants will receive a written copy of the consent form (via email or post) to read through prior to the interview. At the beginning of the interview, the researcher will inform the participant that she will be recording and transcribing the consent process separately. The researcher will check if the participant has read and understood the consent form, and will address any questions at this point. The researcher will ask the participant to state their name, then read through each section of the consent form, asking them to confirm

<p>agreement after each point. Once verbal consent is recorded, the researcher will inform the participant that she is ending the recording of the consent process. The researcher will transcribe the consent process separately and store this in a locked cabinet with signed paper consent forms from face to face interviews.</p> <p>Skype: Prior to beginning the interview, participants will be made aware that the internet cannot be guaranteed to be a completely secure means of communication and will be provided the opportunity to withdraw from the study, or use a different method for interview. Participants will be informed that if they wish to withdraw their data from the study, they will need to inform the lead researcher within 2 weeks of taking part in the study.</p>
<p>15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.</p> <p>As the research may include discussions around traumatic experiences, it is possible that the participants may become distressed. The researcher will remind them of this possibility when discussing consent and will monitor any potential distress throughout the interviews. If the participant becomes distressed, the researcher will check if they wish to continue, would like a break, or would like to end the interview. The researcher will be guided by the participant during this process.</p> <p>It is also possible that participants may be distressed following the interview. If participants would like to, the researcher will provide space to debrief and reflect on the interview immediately following it. This will be the limit of the support provided by the researcher following the interview. The researcher will also provide contact information of local support services if the participant requires this. The lead researcher has clinical experience in supporting people in distress, as well as assessing clinical risk. Furthermore, the lead researcher will also contact the external supervisor for support around clinical issues, and will have the details of the participant's GP should this be needed.</p> <p>Although there is some risk of distress due to discussing past trauma, research indicates that discussing past trauma does not lead to long lasting distress, and is not permanently detrimental to participants, provided it is handled in a sensitive manner (Read, Hammersley and Rudegeair, 2007).</p> <p>Additionally, throughout the interviews, the lead researcher will assess any risks to self or others, as well as remaining aware of any potential safeguarding concerns. The participant will be made aware during the consent process of the limits to confidentiality (see appendix 3 for consent form).</p>
<p>16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).</p> <p>The lead researcher will be conducting the face to face interviews in health centres and community centres near to participants' homes, and as such will keep herself safe in accordance with the [REDACTED] Lone Worker Policy (Appendix 4). This will include operating a "buddy system" whereby details of the location and person to be interviewed will be left in a sealed envelope with the buddy. If the researcher does not contact the buddy by a prearranged time, then the buddy will attempt to contact the lead researcher. If there is no contact made, the buddy will open then envelope and follow agreed escalation procedures. If the researcher does get in touch, then the unopened envelope will be destroyed on her return.</p> <p>The lead researcher will use a Lancaster University research mobile, or phone at Lancaster university to conduct phone interviews, and will use a professional Skype account, so participants will not be provided with any personal contact details during the study.</p>
<p>17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.</p> <p>There are no direct benefits to taking part, however, it is possible that the participants may benefit from talking about their experiences in a positive, growth oriented way that they may not previously have had the opportunity to.</p>
<p>18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:</p> <p>Travel expenses will be paid to participants up to £20 per person.</p>
<p>19. Briefly describe your data collection and analysis methods, and the rationale for their use</p>

Participants will be interviewed face to face, over the phone, or via Skype, in a semi structured interview to gather as much depth on the topic as possible (Please see Appendix 5 for topic guide). Interviews will take place in local health or community centres, during working hours, and the researcher will ensure there will be other staff present. Alternatively, the interviews will take place via phone or Skype at a time convenient to participants.

Face to face: participants will be provided with a consent form (Appendix 3), which will be read through with them prior to beginning the interview and then signed by the participant.

Phone or Skype: Participants will receive a written copy of the consent form (via email or post) to read through prior to the interview and the researcher will gain verbal consent as detailed above.

If interviewing over Skype, participants will be informed that the researcher cannot guarantee secure transmission of data over the internet, and will be given the option to withdraw from the study or arrange an alternative interview method. This information will also be on the participant information sheet.

Interviews will be digitally audio-recorded and transcribed by the lead researcher. The research supervisor will listen to an interview to check style and technique.

Should there be concerns about risk or safeguarding, if appropriate, the lead researcher will inform the participant that she will need to break confidentiality. The lead researcher will contact the external supervisor to discuss the concerns, and will then contact the participant's G.P. if necessary.

The data will be analysed by narrative analysis as this method explores the person's own story of their experience, acknowledging that this story may be influenced by both the participant's and the researcher's personal and social factors. The lead researcher will transcribe the interviews verbatim. Each transcript will be read several times to allow the lead researcher to familiarise themselves with the data, and then the boundaries of narrative segments will be identified. Key events and themes will be identified within the narrative segments and across the transcripts (Riessman, 1993).

20. Describe the involvement of your target participant group in the design and conduct of your research. If you have not involved your target participant group in developing your research protocol, please indicate this and provide a brief rationale/explanation. It is planned that service user involvement will include advice on the topic guide to be used in interviews, as well as draft reads of the final piece of work. Service users will be recruited from LCFT, where the external supervisor has facilitated contact with the service user involvement lead. Due to time pressures, service users have not been consulted about recruitment material.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

Once audio files are transcribed (see section 22), transcriptions will be anonymised. Paper consent forms and transcribed audio consent will be kept in a locked cabinet belonging to the lead researcher, all other data will be stored electronically on a secure server.

Any electronic or paper data containing participants' personal information (such as emails/phone numbers) will be destroyed after the interview has taken place unless a participant expresses interest in checking the themes that emerge from the data. In this case their contact details will be kept until after the themes have been sent to them to confirm they fit with their experience, and then will be destroyed.

At the end of the project, all data will be saved electronically (consent forms will be scanned in and then paper copies will be destroyed), encrypted and password protected and transferred to

Appendix 4-A

Research Protocol

Title: An investigation into the long term stability of posttraumatic growth following an experience of psychosis

Applicant: Natasha Goakes, Trainee Clinical Psychologist, Lancaster University

Research supervisor: Dr Suzanne Hodge, Lecturer in Health Research, Lancaster University

Field Supervisor: Dr Graeme Reid, Consultant Clinical Psychologist/Professional Lead, Step 5 Adult Psychological Services, Lancashire Care

Introduction

Psychosis is an experience where people's reality can become distorted, leading them to experience hallucinations, paranoid beliefs and disorganised thoughts and behaviours (Andreson, Oades and Caputi, 2003). It is not a diagnosis in itself but is associated with diagnoses such as schizophrenia and bipolar disorder (American Psychiatric Association, 2013). A first episode of psychosis (FEP) typically occurs during young adulthood; a time when a person is consolidating their identity and their way of understanding the world (Dunkley, Bates and Findlay, 2013).

Research has suggested that the experience of psychosis can be traumatic (Morrison, Frame and Larkin, 2003). This can be due to the symptoms of psychosis themselves, for instance, hearing voices which can be seen as malevolent, powerful and threatening (Brunet, Birchwood, Upthegrove, Michail and Ross, 2012). Furthermore, the experiences of intervention that accompany an acute episode of psychosis could also be considered traumatic. Intervention may entail strong medication with unpleasant side effects, or at the other end of the spectrum, it may entail community treatment orders, involuntary hospitalisation, or even police involvement (Dunkley et al., 2013). Each of these experiences may individually be traumatic, and often a person will go through more than one of the experiences, multiple times, thus compounding the trauma (Morrison et al., 2003). Furthermore, throughout these experiences, it is likely that people will be experiencing the additional fear of "going crazy", which, as Jeffries (1977) highlighted is a traumatic experience in and of itself. Finally, psychosis can destroy a person's understanding of and assumptions about the world and themselves, and for this to occur during a FEP in young adulthood may lead to the splintering of an emerging sense of self (Jackson and Iqbal, 2000). Birchwood, Todd and Jackson (1998) describe the first two to three years following an experience of FEP as the "critical period", emphasising that this is the point at which a person's mental health is most likely to decline, and also that this is a key time for intervention, in order to best support a person's recovery. In the UK, this is

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typically the time in which Early Intervention Services become involved, providing intense support throughout the critical period (Reading and Birchwood, 2005).

Recovery from psychosis can be understood in various ways. From a clinical perspective, a person may be considered to be recovered if their symptoms reduce and they return to a level of social functioning that is similar to what they experienced before the psychotic episode (Andreson et al., 2003). However, recovery can also mean more than simply controlling symptoms, as highlighted by the recovery movement (Anthony, 1993). For instance, Anthony (1993) describes it as an experience that is personal to each individual, resulting in them leading satisfying and fulfilling lives. With regards to psychosis, a literature review by Andreson et al. (2003) suggested a model of recovery with four domains; finding hope; re-establishment of identity; finding meaning in life; and taking responsibility for recovery. It is evident that recovery can be considered in broad terms, with personal and far reaching consequences for each individual.

It should be noted that, regardless of the way in which recovery from psychosis is understood, it often involves returning to a pre-existing way of being. Some studies suggest that there is an element of personal growth (e.g. Nixon, Hagen and Peters, 2010; Pitt, Kilbride, Nothard, Welford and Morrison, 2007), however, there are few studies expressly investigating the link between the experience of psychosis and growth. One theoretical framework in which to understand this growth is posttraumatic growth (PTG), developed by Tedeschi and Calhoun (2004). Tedeschi and Calhoun (2004) describe PTG as positive psychological change following challenges to a person's way of understanding themselves and their world (Tedeschi, Park and Calhoun, 1998). This change is explained as transformative, leading to a life that is better than it was prior to the trauma. Tedeschi and Calhoun outline the five domains of PTG as "greater appreciation of life and changed sense of priorities; warmer, more intimate relationships with others; a greater sense of personal strength; recognition of new possibilities or paths for one's life; and spiritual development"

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(Tedeschi and Calhoun, 2004, p. 6). Growth can occur in any or all of these domains, and they are not mutually exclusive.

Traditionally, PTG has been investigated in relation to physical illness and other disasters, such as cancer, bereavement, natural disasters, and war (Tedeschi, Park and Calhoun, 1998). However, it is also highlighted that “any life crisis can spark PTG” (Schaefer and Moos, 1998, p.101). Given that psychosis can be considered to be traumatic, it is feasible that people who experience psychosis may go on to develop PTG, however research in this area is limited to two studies (Dunkley, Bates, Foulds and Fitzgerald, 2007; Dunkley and Bates, 2014). Dunkley et al. (2007) carried out case studies of two people with an experience of FEP and their data suggests that people recovering from psychosis can experience aspects of PTG. Dunkley and Bates (2014) found that following an experience of FEP, people use coping strategies in their recovery and that growth is an integral element of this recovery. However, both studies had small sample sizes, and conducted their interviews within months of a person experiencing FEP. Although the participants showed elements of PTG, it was unclear whether this was stable or long term. Additionally, Tedeschi and Calhoun state that people are less likely to develop PTG if they are still experiencing trauma (Tedeschi and Calhoun 2007). A few months after a FEP, a person is still likely to be coming to terms with their experience, and is likely to still be experiencing troubling psychotic symptoms that they have not yet made sense of or learned how to manage (Birchwood et al., 1998). Additionally, in the UK, people will still be receiving support from Early Intervention services, which will be influencing how they understand their experiences (Reading and Birchwood, 2005). Dunkley and Bates (2014) suggest that future research could investigate the further nature and trajectory of growth following an experience of FEP.

This study will therefore build on the current evidence base investigating people’s experience of PTG following FEP. It will explore the ways in which recovery and growth following psychosis relate to PTG and how stable PTG remains over time. The study will interview people who

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have experienced FEP and now consider themselves to have experienced an element of PTG. In keeping with the hypothesis of the “critical period” put forward by Birchwood et al. (1998), and with the importance and influence of support at this time, the study will aim to interview people at least 3 years after their first treated episode of psychosis.

The study will aim to answer the research question, “Can the experience of psychosis lead to stable posttraumatic growth?”

Method

Study Design

As this study is investigating people’s experiences, a qualitative methodology will be used. Participants will be interviewed using a semi-structured interview. Once the data is transcribed it will be analysed using a narrative analysis as this method allows a focus on participants’ narratives of their difficulties of experiencing psychosis, and how they moved to develop elements of PTG.

Participants

Participants will be included if they have had an experience of psychosis, and feel they have experienced one or more elements of PTG. In the recruitment materials elements of PTG will be described as whether “parts of your life are better in some ways than before experiencing psychosis” in order to help potential participants recognise themselves. As the study is investigating trauma, participants will be included if they consider some aspect of their experience of psychosis to be traumatic (this could be the symptoms themselves, or the treatment/intervention).

As narrative analysis will be used the ideal number of participants will be between 8 and 12. The minimum number of participants will be 4. (Riessman, 1993).

To be included in the study an individual must:

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- have had an experience of psychosis, defined as having been assessed as eligible for the First Episode of Psychosis pathway within an early intervention service
- consider some aspect (symptoms, treatment, etc) of their psychosis to be traumatic
- consider themselves to have experienced some element of PTG
- have the ability to give informed consent

Individuals will be excluded if they:

- present a high current level of risk to self or others, assessed by the lead researcher in a screening assessment
- are currently experiencing clinically significant psychotic symptoms (assessed by the lead researcher in a screening assessment using the positive symptoms subscale of the PANSS (Kay, Fiszbein and Opler, 1987))
- have had less than 3 years since their first treated episode of psychosis

Recruitment

Participants will be recruited from support groups, online forums relating to psychosis, and networks such as The Hearing Voices Network and The Paranoia Network. The lead researcher will email moderators of online forums asking to post a message on open discussion boards. On approval, a message will be posted on an open discussion board, describing the study and asking potential participants to contact the lead researcher if they are interested in taking part (please see Appendix 2). The lead researcher will also email facilitators of local network meetings and support groups, asking if she can attend a meeting to discuss the research. At the meeting, she will describe the research and provide information packs, asking potential participants to contact the lead researcher if they are interested in taking part. The researcher will also contact support groups further afield and ask to send through recruitment information to be shared at the next group, if the facilitator feels this is appropriate.

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Once people have expressed an interest in taking part, the lead researcher will carry out a brief screening check to ensure they meet the inclusion and exclusion criteria. The screening will take place over the phone, and will involve a brief discussion of the participant's experience of psychosis and why they would like to take part, an assessment of the current level of risk to self or others, and the use of the positive subscale of the PANSS (Kay, Fiszbein and Opler, 1987) to ensure the participant is not currently experiencing psychosis. Although not designed for use over the phone, the positive subscale can be used in this way and will still be a valid measure of assessing symptoms. The lead researcher will also take a note of the participant's GP in case the participant is currently experiencing psychotic symptoms, low mood, or is otherwise a risk to themselves or others. If, following the screening process, potential participants are felt by the lead researcher to be too high risk for the study, they will be informed of this fact, and the lead researcher will contact the potential participant's G.P.

Recruitment will continue until the required number of participants has been reached. If more than the required number of participants express an interest, participants will be selected on a first come first served basis.

Face to face interviews will be restricted to participants in the north of England, although they will also be offered interviews via phone or Skype. Participants who are based further away will be interviewed via phone or Skype.

If potential participants do not get through the screening because they are experiencing current clinically significant psychotic symptoms, or are a high risk to themselves or others, the lead researcher will inform them sensitively of her concerns, and will share this information with the potential participant's G.P. if necessary. If potential participants do not get through the screening for other reasons (e.g. not having experienced psychosis or do not feel any part of their experience was traumatic), the lead researcher will inform them in a sensitive manner that they are not suitable for the study.

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If potential participants do not meet the inclusion/exclusion criteria, they will be informed of this at the time of the screening assessment, and will also be informed that their contact details will be destroyed. The lead researcher will be responsible for destroying the contact details.

Data Collection

Interviews will be conducted with open ended questions and prompts (please see appendix 5 for topic guide). In an effort to be inclusive, participants can choose to be interviewed in a nearby health or community centre. Participants will be reimbursed for travel expenses up to £20 per person. At the start of face to face interviews, participants will be provided with a consent form (Appendix 3), which will be read through with them prior to beginning the interview and then signed by the participant. In phone or Skype interviews, participants will receive a written copy of the consent form (via email or post) to read through prior to the interview. At the beginning of the interview, the researcher will inform the participant that she will be recording and transcribing the consent process separately. The researcher will check if the participant has read and understood the consent form, and will address any questions at this point. The researcher will ask the participant to state their name, then read through each section of the consent form, asking them to confirm agreement after each point. Once verbal consent is recorded, the researcher will inform the participant that she is ending the recording of the consent process. The researcher will transcribe the consent process separately and store this in a locked cabinet with signed paper consent forms from face to face interviews.

Interviews will last between 1 and 1½ hours and will be audio recorded. The research supervisor will listen to an interview to check style and technique.

During the interviews, if there are concerns about risk or safeguarding, if appropriate, the lead researcher will inform the participant that she will need to break confidentiality. The lead

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researcher will contact the external supervisor to discuss the concerns, and will then contact the participant's G.P. if necessary.

Following interviews, the audio data will be transcribed verbatim.

Data Storage

All paper data (such as transcripts) will be stored in a locked cabinet belonging to the lead researcher. Consent forms and transcribed audio consent will be stored separately. Audio recordings will be transferred to the secure university server as soon as possible after each interview, and set up with password protection, by the lead researcher. The research supervisor will listen to one interview to check style and technique, following this, their copy of the file will be deleted. Once audio files have been transcribed and anonymised, they will be deleted from the recorder. Any electronic or paper data containing participants' personal information (such as emails/phone numbers) will be destroyed after the interview has taken place unless a participant expresses interest in checking the themes that emerge from the data. In this case their contact details will be kept until after the themes have been sent to them to confirm they fit with their experience, and then will be destroyed. All electronic data will be stored on a secure server. Once the study has been completed, consent forms will be scanned and saved and the paper versions will be destroyed by the lead researcher. All electronic data will then be encrypted and will be stored by Lancaster University for 10 years, following which they will be permanently deleted by Lancaster University's Research Coordinator.

Data Analysis

The data will be analysed using narrative analysis. The lead researcher will transcribe the interviews verbatim. Each transcript will be read several times to allow the lead researcher to familiarise themselves with the data, and then the boundaries of narrative segments will be

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identified. Key events and themes will be identified within the narrative segments and across the transcripts (Riessman, 1993).

As an attempt to minimise bias, once themes have been identified, the lead researcher will share the interviews and themes with both supervisors to allow comparison and contrast. Additionally, throughout the analysis, the lead researcher will keep a reflective journal of the process, using this to maintain an awareness of bias and misinterpretation.

Materials

All participants will receive: An information sheet (See Appendix 1)

A consent form (See Appendix 3)

An online message, and a topic guide will also be used (See Appendix 2 and Appendix 5)

Practical issues

Once interview dates have been agreed, if face to face, the lead researcher will arrange to book a room in a GP surgery/community centre.

If participants need to travel to the research interview, the lead researcher will arrange for the reimbursement of their travel costs.

If interviews are taking place face to face, the lead researcher will take appropriate measures in accordance with the [REDACTED] lone worker policy, and will employ a buddy system to ensure her safety. Face to face interviews will also take place during working hours and will ensure there are other staff present in the building.

The lead researcher will liaise with the field supervisor when arranging interviews, for clinical support regarding potential participant distress.

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Interviews will be audio recorded and this data will be transferred as soon as possible to the university server by the lead researcher, where it will be encrypted and password protected. The files will then be deleted from the audio recorder.

Written data will be recorded on the university drive and password protected by the lead researcher.

Paper data such as expression of interest letters or contact details will be stored in a locked cabinet and destroyed as soon as they are no longer required. Other paper data such as consent forms and transcribed audio consent will be stored in a locked cabinet belonging to the lead researcher.

Ethical concerns

As participants will be talking about an experience that they found traumatic, it is possible that they will become distressed during the interview. The researcher will monitor their emotional response to the interview, offering options to continue, have a break, or end the interview as appropriate. The researcher will be guided by the participant with regards to continuing the interview. The field supervisor will provide clinical support to the lead researcher regarding participant distress.

Following the interview, participants will have the opportunity to talk about their experience of the interview, and the researcher will check for any ongoing distress. This will be the limit of the support provided by the researcher following the interview. The researcher will supply information of local services and support should the participant require this.

Timescale

May 2014 – Submit protocol and application to university ethics board

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Jul – Sept 2014 - Decide method for analysis of data. Decide journal for research paper.

Oct – Dec 2014 - Conduct data collection for main study. First draft introduction and method.

Jan - Mar 2015 - Analyse data. Hand in draft introduction and method by end of

January. Write draft abstract, results and discussion sections. Hand in first complete draft of research paper by end of March.

Apr - May - Complete final version of research paper.

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Appendix 4-B



Participant Information Sheet

An investigation into the long term stability of posttraumatic growth following an experience of psychosis

My name is Natasha Goakes and I am conducting this research as a student in the Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to learn if recovery from psychosis can involve positive aspects. For example, if parts of your life are better in some ways than before experiencing psychosis.

Why have I been approached?

You have been approached because I would like to talk to people who feel they have had these experiences:

- An experience of psychosis. This may have involved receiving a diagnosis of psychosis, or schizophrenia, or receiving support from an early intervention service.
- You feel that part of the experience of psychosis was traumatic to you. This could be any part of the experience, such as the symptoms you experienced or the treatment you received.
- It has been at least 3 years since your first treated episode of psychosis (i.e. since you first came into contact with mental health services)
- Since your experience of psychosis, you feel you have either developed a greater appreciation for life, changed your priorities in life, developed warmer or closer relationships with others, feel stronger than you did before, feel that you have more possibilities ahead of you than before, or feel you have changed spiritually.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you choose not to take part there will be no negative consequences to this, and it will not affect your medical care or legal rights.

What will I be asked to do if I take part?

If you decide you would like to take part, I will contact you by phone at a time that is convenient to you, to talk about how you might fit the study, to answer any questions you may have and to check you still want to take part. During this phone conversation, I will also ask you for your GP details. This is in case talking about your experiences of psychosis becomes too upsetting for you, and I need to make sure you have the right support available. I will also ask a few questions about any symptoms you might currently be experiencing, to make sure you are well enough to take part in the research. This is also an opportunity for you to ask any questions you have about the study.

Following this phone conversation, you will be asked to take part in an interview. This will either take place at a health or community centre close to you, or can take place over the phone or over Skype. If we interview in person, I can pay travel expenses for you to get to and from the interview. The interview will take place at a time that is convenient to you. The interview will last between 60 and 90 minutes. Once the interview is completed, this will be the end of your involvement.

Will my data be confidential?

The information you provide is confidential. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be transferred to a secure server and password protected.
- Consent forms will be kept in a locked cabinet.
- All other identifying material will be destroyed as soon as possible.
- Any files on the computer will be encrypted (that means no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, all information from the study will be encrypted and password protected (consent forms will be scanned and saved and paper copies will be destroyed at this point). The data will be kept by Lancaster University for 10 years. At the end of this period they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

Please note:

There are some limits to confidentiality - if you say something in the interview that makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of the research team about this. If possible, I will tell you if I have to do this. If interviewing via Skype, it is important to be aware that the internet is not a guaranteed secure method of communication.

What will happen to the results?

The results will be summarised and reported for assessment by the university and may be submitted for publication in an academic or professional journal.

Are there any risks?

As I will be asking you about your experiences of psychosis, it is possible that you may become upset or distressed during the interview. If this happens, it will be your choice about carrying on with the interview, taking a break, or ending the interview altogether. I will provide details of local support services should you feel you need them. If you become very distressed, I will contact your GP to make sure you get the support that you need.

Are there any benefits to taking part?

There are no direct benefits to taking part, but you may find it helpful to talk about any your experience of psychosis in a positive way.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Natasha Goakes Email: n.goakes@lancaster.ac.uk Tel: 07852515788

Alternatively, please contact:

Suzanne Hodge Email: s.hodge@lancaster.ac.uk Tel: 01524 592712

Graeme Reid Email: graeme.reid@lancashirecare.nhs.uk Tel: 01695 598 498

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Jane Simpson,

Ethics

Senior Lecturer

Division of Health Research

Lancaster University

Lancaster

LA1 4YG

Tel: (01524) 592858 Email: j.simpson2@lancaster.ac.uk

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Prof Roger Pickup,

Associate Dean for Research,

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences),

Lancaster University,

Lancaster LA1 4YD

Tel: (01524) 593746 Email: r.pickup@lancaster.ac.uk

What do I do if I would like to take part?

If you would like to take part, or if you would like further information about the study, please contact the lead researcher, Natasha Goakes.

You can call on 07852515788

Or email on n.goakes@lancaster.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 4-C

Letter for online message boards/forums



Hi,

My name is Natasha Goakes and I am a trainee Clinical Psychologist at Lancaster University. I am doing some research on people's experience of recovery from psychosis. I have ethical approval for this study from Lancaster University.

I am hoping to talk people who have had an experience of psychosis, and consider that experience to have been a difficult one, or a traumatic one. The difficult part of the experience could be from the symptoms you had, or the treatment and intervention you received. I would like to talk to you if you now feel that since your experience of psychosis, you have either developed a greater appreciation for life, changed your priorities in life, developed warmer or closer relationships with others, feel stronger than you did before, feel that you have more possibilities ahead of you than before, or feel you have changed spiritually.

If you would like to learn more about this study, or are interested in taking part, please contact me on:

Tel: 07852515788

Email: n.goakes@lancaster.ac.uk

Thank you for taking the time to read this information,

Natasha

Appendix 4-D



Consent Form

Study Title: An investigation into the stability of posttraumatic growth following an experience of psychosis

We are asking if you would like to take part in a research project which aims to learn about the link between posttraumatic growth and psychosis.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Natasha Goakes.

Consent form

Please initial box after each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been examined.
5. I understand that the audio recording and/or transcript of my interview may be shared with the interviewer's supervisor.
6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
7. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.
8. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.
9. I consent to information and quotations from my interview being used in reports, conferences and training events.
10. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research supervisor.
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.
12. I consent to take part in the above study.

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Name of Participant _____ Signature _____ Date _____
Name of Researcher _____ Signature _____ Date _____

Appendix 4-E

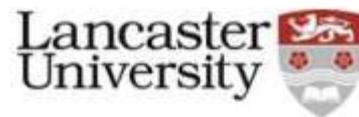


Topic Guide

Question	Prompts
Can you tell me about your experience of psychosis, starting from when you first realised something was different?	What do you remember about becoming unwell? What was your first contact with services? How did you feel about receiving support from services? Did you meet anyone else with similar experiences?
Can you tell me about your “recovery”, whatever that means to you, starting with when you first felt that you were “recovering”?	Do you remember recovery being a slow process, or one that happened quickly? Did you recognise it yourself, or did other people mention things that made you realise what was happening?
Can you tell me a little bit about your life now, in comparison to your life before experiencing psychosis?	Do you feel you have developed a greater appreciation for life? Do you feel you have changed your priorities in life? Do you feel you have developed warmer or closer relationships with others? Do you feel stronger than you did before? Do you feel that you have more possibilities ahead of you than before? Do you feel you have changed spiritually?

Appendix 4-F

Final University Research Ethics Committee Approval Letter



Applicant: Natasha Goakes
Supervisor: Suzanne Hodge
Department: Health Research
FHMREC Reference: FHMREC15050

15 February 2016

Dear Natasha

Re: An investigation into the stability of posttraumatic growth following an experience of psychosis.

Thank you for submitting your research ethics amendment application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Diane Hopkins (01542 592838 fhmresearchsupport@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins".

Dr Diane Hopkins
Research Development Officer

CC Ethics@Lancaster; Professor Roger Pickup (Chair, FHMREC)