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HOLLY TETT BSc MSc

MAJOR RESEARCH PROJECT

Understanding how self-harm functions for individuals

Section A: A literature review exploring the functions of self-harm in adults

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Section B: “It’s the way I cope”. How do people who hear voices and also self-harm understand the relationship between the two?

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

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SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

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Summary of the Major Research Project

Section A: A literature review exploring the functions of self-harm in adults

A critical review of empirical literature was conducted to explore the potential functions of self-harm in adults. Eleven articles were selected to review following the literature search. Results suggested that self-harm functioned as emotional regulation for a majority of participants. Other functions included to gain a feeling of control over a situation, to display distress or to punish the self or others. The need for individualised care for people who self-harm was highlighted as well as avenues for future research.

Section B: “It’s the way I cope”. How do people who hear voices and also self-harm understand the relationship between the two?

A grounded theory study was carried out analysing the accounts of 12 participants with experience of voice-hearing and self-harm. Self-harm was clearly defined as a way of coping with negative voices. Within the larger umbrella of ‘coping’, individual functions of self-harm included: as emotional regulation, as a response to fear of judgement from others, as a way of help-seeking and as a way of seeking control. Service-user led staff training and focusing on identifying other coping methods were examples of suggestions for future clinical work.

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Section A

A literature review exploring the functions of self-harm in adults

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Abstract

Aims

Although it has increased in prevalence in recent years, a full understanding of the possible functions of self-harm for individuals has not yet been established. This review aimed to collate recent empirical findings in this area regarding this issue and also to identify knowledge gaps in this area. The objective was to synthesise the findings to inform future clinical and empirical understanding and practice.

Methods

Databases were searched for articles focused on understanding the function of self-harm in adults. Articles were included if they (a) had been published since the most recent existing review or (b) had not been in that review.

Results

Self-harm appeared to function as a form of emotion regulation for a large number of individuals. For others (or sometimes additionally for the same individuals) it appeared to function as a form of control over a situation, as a method of displaying distress or as a way of punishing the self or others. These results were considered in the context of the quality of the studies under review.

Conclusions

Self-harm appears to fulfil different functions for different individuals at different times. This has significant implications for clinical practice, namely that care should be based on an individualised formulation, which recognises the possible functions of self-harm for service-users. There are also empirical implications, including the need for a model to show the different functions of self-harm and how they might interplay. Future research that focuses on emotional regulation as a function would provide further useful insights.

Key words: self-harm, function, adults

Introduction

It has been estimated that in the Western world, approximately five percent of adults have self-harmed at some point during their lives (Klonsky, Oltmanns & Turkheimer, 2003) with the prevalence of self-harm seeming to have increased in recent years (Muehlenkamp, 2005). Indeed Clements et al (2015) found that collectively, A&E departments in the United Kingdom logged 13,437 attendees for help with self-harm injuries between 2010 and 2012. These figures also, of course, do not account for the people who did not require, want or were not able to seek medical help for their injuries. This highlights that self-harm is a significant national issue.

Empirical research in this area has tended to focus on young people (Hawton, Rodham, Evans & Weatherall, 2002; Laye-Gindhu & Schonert-Reiche, 2004) but increasingly there has been more awareness of self-harm in adults too (Clarke, Baker, Watts, Williams, Feldman & Sherr, 2009; Moran et al, 2012). Across age, self-harm has often been linked to emotional distress (Chapman, Gratz & Brown, 2006). The potential associated social difficulties that may be linked to self-harm in conjunction with emotional difficulties might have a profound effect on wellbeing. Some individuals have described, for example, experiencing prejudice from others because they have self-harmed. (Pembroke & Smith, 1998). This potential prejudice might account for the limited information available about the nature, function and prevalence of self-harm. It is possible that a great number of people do not seek help for their self-harm for fear of how they will be perceived by others (Pembroke & Smith, 1998). Developing a better understanding of why adults self-harm therefore seems important. This review will examine the relevant literature in an attempt to ascertain current understanding. Firstly, self-harm will be defined and current understanding explored. Following this, recent empirical research focused on the function of self-harm in adults will

be reviewed and their methodologies critiqued. Finally, appropriate clinical and research implications will be considered based on the findings of the review and the related critiques.

Defining Self-harm

Self-harm, which can be defined as intended injury to one's own body, (Herpertz, 1995) is known by a multitude of different terms, both clinically and in the general population (Curtis, 2006). Historically, self-harm was referred to as self-mutilation (Favazza, 1998), a term which now might be considered unpleasant or gruesome. Terms such as these are perhaps reflective of the disdain with which people who self-harm can often be viewed societally (Urquhart-Lawet , Rostill-Brokkes & Goodman 2008).

More recently, causing non-accidental injury to oneself has been termed either self-harm, self-injury or deliberate self-harm (DSH) and upon being given its own classification in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013), non-suicidal self-injury (NSSI) (Glenn & Klonsky, 2013). The latter distinguishes self-harm from attempts to take one's own life. The decision to assign it a distinct diagnostic category as a 'syndrome' was contentious in view of the link made by some studies between self-harm and suicide attempts (Stanley, Gameroff, Venezia-Michalsen & Mann, 2001). DSM-5 (DSM-5, American Psychiatric Association, 2013) criteria for 'NSSI' include amongst others 'Five or more days of intentional self-inflicted damage to the surface of the body without suicidal intent within the last year'. Some authors (e.g., Creswell, 2005) have suggested that designation as a syndrome in this way unhelpfully promotes a solely medical understanding of the phenomenon (discussed further below).

As an alternative to these umbrella terms, others describe particular types of self-harm, for example, "cutting". Other examples include head-banging, burning and not

allowing wounds to heal (Whitlock, 2010). The plethora of names for the act of causing purposeful injury to oneself is perhaps reflective of the very individual and personal nature of the experience (MacAniff-Zila & Kiselica, 2001). For clarity, the current review will use the term “self-harm”.

Self-harm in adults

Much research into self-harm has focused on an adolescent population (Hawton, Harriss, Hill & Simpkin, 2003; 2002; Laye-Gindhu & Schonert-Reiche, 2004) in terms of both the functions of self-harm for the young person and the possible clinical treatment. However, self-harm is also something that is experienced by adults (Clarke et al, 2009; Moran et al, 2012) and which can be a significant part of their lives.

Although both empirically and theoretically self-harm has nearly always been thought of as a display of distress, (Hawton, Saunders & O’Connor, 2012) it is often conceptualised in different ways. Psychiatry and the medical model for example, tend to describe it as a symptom of a mental illness, for example schizophrenia (e.g., Haw, Hawton, Sutton, Sinclair & Deeks, 2005) or of a personality disorder such as borderline personality disorder (Andover, Pepper, Ryabchenko, Orrico & Gibb, 2005). This could be argued as helpful because viewing self-harm as symptom of an illness or disorder might mean it is not viewed as the ‘fault’ of the individual. Palmer, Blackwell & Strevens, 2007 suggested that service users have felt they did not receive an adequate standard of care when presenting to A&E. It was further suggested that one of the reasons for this might have been because staff viewed the self-inflicted nature of self-harm as less deserving of treatment than other injuries or illnesses. It is therefore possible that service users might be less judged by A&E staff if it was felt that their self-harm was a symptom of illness rather than something they could control.

Conversely, some service user accounts have suggested that self-harm being labelled as a symptom has had detrimental effects. These include having prevented healthcare workers and members of the public from understanding the distress behind the self-harm and the functions it might have for people (Pembroke, 2006). Similarly, it could be argued that self-harm should be considered an individual experience and that categorising it as a symptom does not allow it to be viewed in this way. Horrocks, Hughes, Martin, House and Owens, (2005) also suggested that this might have a negative 'one size fits all' impact on the type of treatment offered to service-users who seek individual help within mental health settings.

As discussed above, Psychology has tended to view self-harm as a functional behaviour although it is still not clear from research how varied these functions might be. It is evident there are currently many interpretations or ways of categorising self-harm in adults.

Understanding self-harm

As repetitive self-harm has become more prevalent in Western society (Hawton et al, 2003) and stigma towards those affected has appeared ever-present (Urquhart-Law, Rostill-Brokkes, & Goodman, 2008) it is clear better attempts need to be made to understand the function of self-harm for people. The current lack of awareness and understanding appears to have significant practical consequences for those affected: some who self-harm describe being discriminated against by society in the form of bullying, harassment and ostracisation (Hodgson, 2004). Perhaps more concerning still, is research suggesting that people who self-harm also experience prejudice and discrimination from healthcare professionals. This has been described both when seeking practical help (for example when requiring stitches for wounds in A&E) (Cooke, 2013) and when seeking emotional support from mental health services (Warm, Murray & Fox, 2002).

Long, Manktelow & Tracey (2012) suggested that one reason for the prejudice experienced by those who self-harm could be the general lack of understanding within society of its possible functions. However, the finding that this prejudice appears to extend to health professionals is particularly sobering. Few authors explore likely reasons for this, but it seems possible that some professionals also have little understanding of the nature and functions of self-harm (Pembroke, 2006). NICE guidelines seem to reflect this with little guidance on specific psychological interventions that have an evidence base for the treatment of self-harm (NICE, 2013).

Some research has suggested that self-harm may have multiple functions, including relief from emotional pain (Babiker & Arnold, 1997) and seeking care from others (Scoliers, et al, 2008).

Models for understanding the function of self-harm have been put forward such as the Experiential Avoidance Model (EAM) (Chapman et al, 2006). This model suggests that self-harm functions as a way to escape mental anguish: physical pain leads to dissociation. The model suggests that when presented with a stimulus that elicits a negative emotional response, certain individuals (for example, those who find it hard to tolerate distress as a result either of inherited traits, life experiences or both) will self-harm in an attempt to avoid feeling negative emotions. This then results in temporary relief as the emotions are pushed to one side while the individual focuses on harming themselves. Self-harm is then negatively reinforced by the temporary subduing of negative emotions and so becomes a habitual response to certain stimuli.

Relatedly, Attachment Theory (Bowlby, 1969) provides one explanation as to why some individuals might find emotional regulation difficult and need an outlet (such as self-harm) in order to cope with difficult emotions. Poor attachment to a care-giver in childhood

has been linked to the development of difficulties with emotional regulation as an adolescent and adult (Fonagy, Gregety, Jurist & Target, 2002) because the care-giver either did not respond appropriately to infant distress or was not able to model methods of self-soothing when distressed. Never having learnt the skills to manage their own distress, individuals may develop their own distress-management techniques as adults (including potential self-harm).

In an attempt to find a coherent explanation for the functions of self-harm, Klonsky (2006) conducted a review of empirical research in this area. The majority of these studies were self-report and the remaining were laboratory studies examining the direct physiological effects on arousal of self-harm. The results suggested that self-harm predominantly served as an affect-regulation function with individuals experiencing negative affect prior to self-harming and reduced negative affect post self-harm. Several studies also found support for self-harm functioning as a form of self-punishment. Moderate support was found for the notion of self-harm acting as an escape from dissociation, a way of controlling suicidal urges, a way of feeling something (an escape from feeling numb) and as a means of interpersonal communication. The article did not delineate whether the specific findings applied to different people or the same people at different times. However, they did make clear that the overall results were consistent across different participants regardless of age, gender, clinical or non-clinical and across mental health services.

Rationale for and aims of this review

The Klonsky (2006) review was conducted over a decade ago including papers up to 2004. Since that time self-harm has increased in prevalence (Muehlenkamp, 2005) and so been more of a focus in clinical work. It is therefore important to build on the existing review by examining more recent empirical research in this area.

In particular, Klonsky's (2006) review made recommendations for future research which included investigations into changes in affect associated with self-harm, more detail about how self-harm regulates affect, thinking about how assessing individual self-harm function can inform care-planning and broader research samples (community sampling as well as inpatient for example).

Alongside the utility of examining how research in this area might have progressed, the current review will include two papers that were not included in the original review. Their absence was considered a limitation of Klonsky's (2006) work that will be addressed by including them here. One of these (Huband & Tantum, 2004) met the inclusion criteria for Klonsky (2006) and was presumably excluded because it was published after the literature search had been completed. No further explanation was given. The second (Harker-Longton & Fish, 2002) was presumably excluded because it also explored suicidal behaviour alongside self-harm (part of the exclusion criteria for Klonsky (2006)). The decision not to follow the same criteria here was made because research has found links between self-harm and suicide (Hawton, Zahl & Weatherall, 2003). This suggests that they are not mutually exclusive and so might occur naturally together in conversation with participants.

Additionally, it is important to consider, as discussed above, the role of prejudice further negatively affecting self-esteem. It lends further weight to the increased need for better understanding and awareness of the function of self-harm. Additionally, it is possible that the apparently different ways of thinking about self-harm function (from the point of view of service-user movements, psychology and psychiatry) propagates distress. This is conceivable because service user opinion might clash with some professionals.

With these needs in mind, the current review will provide a detailed summary and critique of published literature, from the year 2004 onwards, that has explored the functions

of self-harm in adults. It will also include the two papers that were excluded from the previous review as discussed above (Klonsky, 2006).

This review has three aims. Firstly, to consider what function self-harm serves for people, secondly whether the empirical understanding of the functions of self-harm has developed or changed since the previous review, and if so how, and thirdly to identify knowledge gaps in this area. In doing so, it is hoped that the clinical care (by mental health and physical health services) of individuals who self-harm can be improved. Within wider society an increased understanding and awareness of why people self-harm, might help to reduce discrimination and improve access to help.

Methodology

Literature search strategy

Three databases were used for the literature search (PsychInfo, Web of Science and Ovid Medline) which was conducted in January 2017 (see Figure 1 for search strategy). Search terms used were:

- (self-harm* OR self-inj* OR cut* OR DSH OR NSSI)
- AND (use* OR meaning OR reason* OR function* OR why OR cause*)

Searches undertaken using additional descriptive terms for self-harm (aside from cutting) such as “burning” did not yield further research hence these were not included.

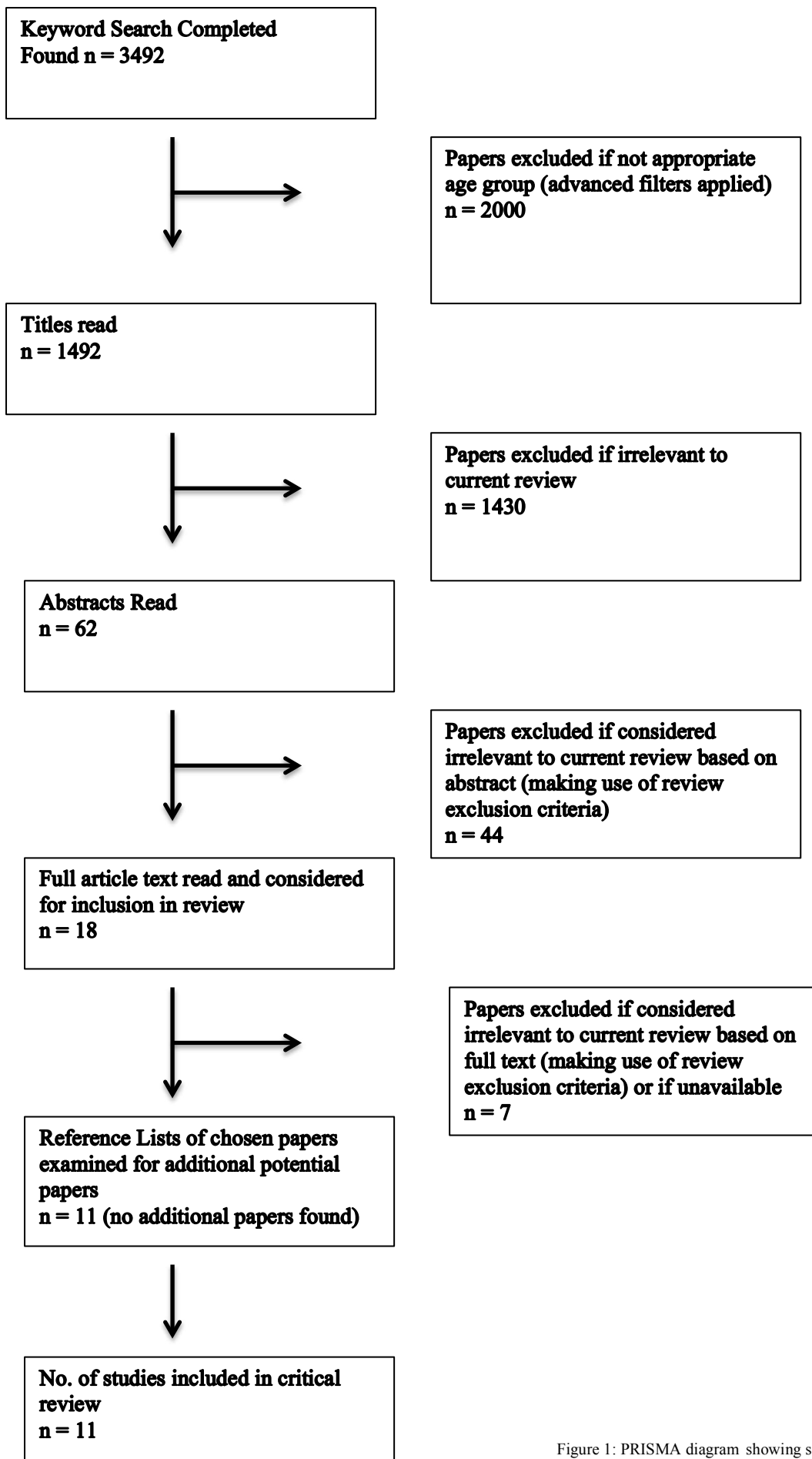


Figure 1: PRISMA diagram showing search strategy

Table 1 shows the inclusion and exclusion criteria for the review. Studies prior to 2004 were not included (with the exception of the two previously excluded studies) because these had been reviewed previously (Klonsky, 2006). The search yielded 11 studies to be discussed within this review.

Table 1: Review inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Studies that focus primarily on and present data about the function of self-harm	Studies where the primary focus is on something other than the function of self-harm
Studies that present data about self-harm that is not exclusively in the context of suicidal ideation nor attempt	Studies that examine self-harm exclusively in the context of suicidal ideas or attempt
Studies in which participants had a mean age of at least 18 years	Studies in which participants had a mean age of less than 18 years
Studies published from 2004 onwards with the exception of studies that were excluded from the previous review	Studies published prior to 2004

Structure of the review

The review will attempt to identify the possible functions of self-harm in adults by examining the findings of the eleven identified studies and providing an in-depth analysis of these, grouped according to themes. A methodological critique will follow and finally, conclusions will be drawn and future research and clinical implications discussed.

The Review

Description of studies

Design.

All but two of the studies, namely, Klonsky (2009) and Glenn & Klonsky (2010) were qualitative in design. The emphasis on qualitative research revealed the authors' desire to hear directly from participants about their experiences and beliefs about the functions of self-harm using their own words.

Participants.

All studies had adult participants with a mean age of over 18. Participants numbers ranged from one (Harker-Longton & Fish, 2002) to 154 (Polk & Liss, 2009) and they were recruited from the United Kingdom, the United States and Norway. All participants, except some of those in Scourfield, Roen and McDermott (2011), had personal experience of self-harm. The latter study included participants with and without experience of self-harm: the authors stated that they wished to examine a broader range of thoughts on self-harm function.

Overview of findings.

Overall findings and themes shared by the studies will be described (the themes will be highlighted in bold for clarity). Table 2 shows further detail regarding the methodology and findings of each study.

Table 2: Detail of study methodology and findings

Paper Title & Author	Aims/Research Question	Hypothesis	Participants	Study Design & Methodology	Country carried out in	Measures	Findings	Quality Score
Cutting doesn't make you die (Harker-Longton & Fish, 2002)	To explore an individual's subjective experience of self-harm	None detailed	N=1 (female) Recruited from a medium secure unit for adults with intellectual disabilities and associated difficulties	Qualitative: Single case study, phenomenological design	United Kingdom	None	Self-harm was carried out because: -Of a fear of getting better -For release of frustration -As punishment for being 'dirty' -A 'rush of steam' coming out	+ / ++
The non-display of authentic distress: public-private dualism in young people's discursive construction of self-harm (Scourfield, Roen & McDermott, 2001)	To discover and analyse the ways in which individuals make sense of why people self-harm	None detailed	N=69 Aged 16-25 Recruited from schools, colleges, universities, youth clubs and social welfare organisations	Qualitative: Thematic Analysis and Discourse Analysis	South Wales and North England	None	Self-harm was considered authentic and illustrative of genuine distress if kept private but 'attention-seeking' only if displayed publically	+

The role of seeing blood in non-suicidal self-injury (Glenn & Klonsky, 2010)	To examine the role of seeing blood in self-harm and how this fits with the function of self-harm	That seeing blood in self-harm relieves unpleasant emotions and gives the individual a sense that they have self-harmed 'properly'	N=64 young adults from a college population Participants had a history of self-harm using cutting	Between groups comparison study (important to see blood vs not important to see blood) on a number of variables tested. Made use of questionnaires and structures interviews.	United States	Yes	Self-harm and seeing blood were associated with: -Emotional release (to relieve tension and to calm down) -Those who felt the need to see blood when they self-harmed were more likely to self-harm more severely and for longer durations overall -Those that needed to see blood were more likely to meet criteria for bulimia nervosa and /or BPD	+
Repeated self-wounding: Women's recollection of pathways to cutting and value of different interventions (Huband, & Tantam, 2004)	To identify what pathways lead to self-harm To explore participant experience of the methods used by staff to try to decrease frequency of self-harm	None detailed	N= 10 (all female) All participants had been in contact with professional services	Qualitative: Grounded Theory	United Kingdom (within a small location)	Yes	- Self-harm took place when there was a steady increase of tension (spring pathway) or when participants switched on the impulse to self-harm (switch pathway) - Long term relationships with staff viewed as helpful - Intervention usefulness was reduced when the person delivering the intervention was not responsive to the person's needs	++

Emotion and self-cutting: Narratives of service users referred to a personality disorder service (Morris, Simpson, Sampson & Beesley, 2013)	To explore emotion across the lifespan in relation to self-harm and to improve understanding of the contexts in which difficult emotions occur	Participants who had learnt poor emotional regulation skills as children would struggle to cope with difficult emotions in adulthood thus turning to self-harm to help them to regulate these	N=8 participants (7 women and 1 man). Participants aged between 21 and 51. Had cut themselves at least 5 times for a duration of 1 year Recruited from a personality disorder service	Qualitative design: Narrative Analysis	Not detailed but all participants described themselves as 'white British' which gives an indication that the study was carried out in the UK	None	-Act 1 – Participants described not being allowed to show emotion (even in the context of abuse) as a child -Act 2 – Participants described self-harm as a release from a build up of emotions or to deal with emotions that cannot be processed. Additionally it was used by some as a way of turning angry feelings towards others in on themselves as they felt ultimately to blame, as a way of calming racing thoughts or reversing a feeling of numbness -Self-harm like a vicious cycle -Self-harm made them feel different from others in society	++
Exploring the motivations behind self-injury (Polk & Liss, 2009)	To gain a clearer understanding of people who self-harm and why they do	None	N-154 (139 females, 16 males) Mean age – 22.67 years Recruited from a self-harm website	Qualitative: Phenomenological design	Not stated, however, study was carried out online	None	Self-harm was used to: -Gain an emotional release - To feel alive or real and stop feelings of dissociation. - To feel more in control -To punish the individual -To distract from suicidal or	++

							homicidal thoughts or actions	
The functions of self-injury in young adults who cut themselves: Clarifying the evidence for affect-regulation (Klonsky, 2008)	To measure the affect experience brought about by self-harm and hear from participants regarding which aspects of self-harm they consider most important	Not clear	N=39 young adults who had self-harmed repeatedly. Participants had reported 5 non-suicidal skin cutting episodes on the screening measure used and also at the interview stage. Unclear where participants were recruited from	Quantitative: Cross-sectional. An author designed structured interview assessing prevalence and nature of self-harm	United States	Self-harm screening measure developed by the author based on measures used in previous research	-Self-harm was used to regulate emotion -Self-harm was associated with improved affect (a decrease in high arousal negative affect and an increase in positive affect) -Participants who had most improved affect cut themselves more frequently	-/+
Hurting no-one else's body but your own: People with intellectual disability who self injure in a forensic service (Duperouzel & Fish, 2010)	To capture the experiences of individuals with intellectual disability who self-harm within a forensic service	None detailed	N= 9 participants Participants had experience of self-injury without intent to commit suicide Participants all had diagnoses of mild-moderate Intellectual Disability. All had been detained within secure services	Qualitative: Phenomenological	United Kingdom	None	-Participants felt that self-harm helped them to cope when feeling emotionally distressed -Participants reported often feeling guilty after having self-harmed which ultimately could lead to further self-harm so as to cope with these feelings -Inpatient service response to self-injury was considered unhelpful and too restrictive	++

			for between 2 and 8 years at the time of the study				-Participants indicated that adequate emotional support from staff would have helped to prevent self-harm and promote recovery	
			Participants had capacity to consent to the study and were articulate					
Cutting to live: A phenomenology of self-harm (Brown & Kimball, 2013)	To explore directly with individuals who self-harm about what it means for them	None detailed	N=11 (10 females and 1 male) Participants were recruited from a self-selected response to a University announcement All participants had engaged in self-harm behaviours and made attempts to stop Participants had been self-harming for between 2 and 24 years	Qualitative: Phenomenological	Not stated	None	-Self-harm is misunderstood (self-harm is not suicide and self-harm is an addiction, self-harm progresses and is linked with isolation) -Self-harm is linked to trauma (it is difficult to express emotion and difficult to cope) - Some professional help is not helpful -Self-harm has a purpose (is can be a release, it can be a way of punishing the self, physical pain can help to manage emotional pain, self-harm can make one feel more in control of life) -Participants wanted professional staff to be non-judgemental, get educated about the function of self-harm and understand that self-harm does not equal	++

suicidal thoughts

<p>From feeling too little and too much, to feeling more and less? A non-paradoxical theory of the functions of self-harm (Horne & Csipke, 2009)</p>	<p>To create a theory of self-harm that is paradox-free and relevant to people who self-harm</p>	<p>None detailed</p>	<p>N=37 (34 female, 3 male)</p> <p>Recruited from self-selected respondents to an online questionnaire</p>	<p>Qualitative: Grounded Theory</p>	<p>Based in UK but recruited participants from UK and US</p>	<p>None</p>	<p>-Three domains of emotional awareness, sense of reality and body-based experience all share characteristics of “feeling too little” and ‘feeling too much’</p> <p>-Self-harm increases the connection with the body and feeling emotion</p>	<p>++</p>
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<p>Pushing the boundaries: Understanding self-harm in a non-clinical population (Straiton, Roen, Dieserud & Hjelmeland, 2013)</p>	<p>Not clear</p>	<p>None stated</p>	<p>N=122 (96 females, 25 males, 1 unreported gender)</p> <p>Mean age of participants was 22.62 years</p> <p>Recruited from a sub-sample of participants who had completed an online questionnaire asking about self-harm and suicidal thoughts and actions.</p>	<p>Qualitative: Thematic Analysis</p>	<p>Norway</p>	<p>None</p>	<p>- The most common type of self-harm was cutting</p> <p>-76% had self-harmed more than once</p> <p>-29% had used more than one method of self-harm</p> <p>-Self-harm was associated with social influences (such as being bullied) and a way of expressing negative emotions</p> <p>-Self-harm was a way of escaping emotions, feeling something, to communicate distress, to punish others, affect change, to gain control.</p> <p>Self-harm was experienced as shameful by some</p>	<p>+</p>
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participants

Emotional Regulation and coping.

All studies suggested that **emotional regulation** and **coping with difficult feelings** were primary functions of self-harm. Predominantly, participants described self-harming to release tension and feeling calm and relieved following the act. Polk & Liss (2009) also found that self-harm could function as a way of breaking out of a dissociative state.

Brown & Kimball (2013) suggested that this can feel like somewhat of a paradox with some individuals indicating they sometimes **self-harm to feel something other than numb** (seeking affect) but **self-harm to escape from intense feelings** such as anger or sadness (shunning affect) at others.

Indeed, Huband & Tantum (2004) found that participant identified functions fitted into two pathways; the 'switch' pathway and the 'spring' pathway. Huband and Tantum's (2004) 'switch' pathway was initiated when individuals were choosing to self-harm to 'switch on' or to 'feel something'. The 'spring pathway' represented a threshold of tension or intense feelings being breached.

Brown & Kimball (2013) identified a way of explaining how these different individual experiences might be linked. They suggested that seeking and shunning affect do have shared characteristics including having increased emotional awareness and a sense of self, be it in a heightened or diminished sense. In this way, it appears that self-harm functions to restore equilibrium within the individual.

The notion of self-harm functioning as a release or escape from difficult emotions was also considered in the single case design study (Harker-Longton & Fish, 2002). Here the participant described feeling "upset" before cutting and "happy" afterwards. The simplicity of these contradictory descriptives is striking. Similarly, Glenn & Klonsky (2010) found that in those of self-harm and felt the need to see

blood when they hurt themselves, 84.8% associated seeing blood with a decrease in tension and 72.7% with an increased feeling of calm, lending further support to this theory.

Another clear theme in relation to emotional regulation involved self-harm (physical pain) serving as a 'swap' for emotional pain. Brown & Kimball (2013) included extracts from participant interviews such as, "It was me trying to focus on something besides what I was feeling inside." (p. 202) and "You just want to match an emotional pain with a physical. And at that moment when you're cutting, it doesn't hurt, but it's something physical to see, to touch. It's tangible". (p. 202). This suggestion that self-harm may function to 'swap' physical pain for unbearable emotional pain appears in several studies. Horne & Csipke (2009) quote "The pain...gives my mind a concrete feeling that is logical to focus on, rather than absent feelings" (p. 661) and Straiton, Roen, Dieserud & Hjeelmeland (2013) quote "I cut my wrists intentionally to transfer the pain to something concrete and something I could see" (p. 80) . It appears that self-harm was both a reliable and concrete way of managing difficult emotions in situations where naming or addressing them directly felt too uncertain or overwhelming and therefore unsafe.

Control.

The idea of self-harm functioning as a form of control was suggested in several of the studies. Klonsky (2009) & Polk & Liss (2009) found that individuals described using self-harm as a way of controlling suicidal or homicidal thoughts and preventing themselves from acting on them. Polk & Liss (2009) also detailed that 18% of their sample of 154 identified control as a key function of self-harm with one participant saying "I cut to make myself feel that I still have the power to handle a

situation” (p. 237). Similarly, a participant in Brown and Kimball (2013) described self-harm as “a way of controlling my life” (p. 202).

The potential link between self-harm functioning as a method of emotion regulation or coping and as a method of control is clear. As above, self-harm appeared to have a calming function for some and it is arguably much easier to think clearly when our thoughts are settled and calm.

Punishment.

Participants in Morris et al (2015) felt that self-harm functioned as self-punishment, as anger being “turned inwards” (p. 128) and as a manifestation of “self-hatred’ (p. 128). These ideas were echoed in Klonsky (2009) who found that 69% of participants agreed they had self-harmed to “express anger at (themselves)” (p. 263); however, this was usually seen as a secondary reason (primary reasons often being for emotional relief, to gain control over difficult feelings and to banish difficult emotions). A participant in Harker-Longton & Fish (2002) also stated that “I used to feel like I had to punish myself, for being dirty” (p. 143). Similarly, in Polk & Liss, (2009) 10% of the participants indicated that they cut themselves as self-punishment. One participant said, “I feel deserving of my wrongdoings and if that punishment doesn’t come from anywhere else, it will come from me” (p. 237).

Communicating distress.

Scourfield et al (2011) found that when discussing the function of self-harm, participants appeared to make a dichotomous distinction between self-harm as an expression of ‘real distress’ (seen as understandable and worthy of sympathy) and self-harm which was a ‘self-indulgent’ way of ‘attention seeking’ (viewed as an invalid reason to self-harm). Participants felt that these categories were quite distinct,

represented different types of people self-harming for different reasons and did not discuss the option of self-harm functioning as both distress reduction and also being a way to seek care from others within the same episode. Participants did not consider the idea that that self-harm could have either function depending on context.

In Straiton et al (2013) one participant described using self-harm as a way of communicating their distress to someone who had wronged them: “I wanted someone, who had physically hurt me to understand how much pain I had inside me” (p. 80).

The theme of communication of distress did not appear in all studies, but where it was mentioned participants saw it as a major function of their self-harm.

Summary of findings.

All of the studies made reference to self-harm having an emotion-regulation function, although for different individuals it was described as either reducing or increasing affect.

Other possible functions included communicating distress, control, and punishment of the self and /or others. It was clear that self-harm fulfilled different functions for different individuals: there were individual differences even within the broad categories of function just described.

Methodological Critique

The review detailed the findings of 11 research studies. Nine of these were qualitative in design and the remaining two quantitative. This section will first analyse and critique the qualitative studies, followed by the quantitative. The critique will draw on National Institute for Clinical Excellence guidance on appraisal of these types of studies (NICE, 2012) (see Appendix A for details of the appraisal checklists).

An overall quality rating was assigned to each study based on these guidelines (Table 2).

Quality of Qualitative Studies

Suitability of qualitative approach.

The studies that made use of a qualitative design (all with the exception of Glenn & Klonsky, 2010 and Klonsky, 2008) all did so for appropriate reasons. Each study was designed to gather data about the first-person subjective experience of self-harm and to attempt to gain an understanding of the function of self-harm for those participants. This was also useful because self-harm is an under-researched area and so it might be difficult to know what kinds of questions to ask in quantitative studies. Scourfield et al (2011) was a slight exception to this in that it also sought data regarding the views of non-self-harmers (also students) about the functions of self-harm.

The Harker-Longton & Fish (2002), Duperouzel & Fish (2010) and Brown & Kimball (2013) studies used a phenomenological design, Huband & Tantum and Horne & Csipke (2009) grounded theory, Morris et al (2015) narrative analysis, Straiton et al (2013) thematic analysis, and Duperouzel & Fish (2010) thematic and discourse analyses. Polk & Liss (2009) neglected to detail the design used although it appeared to be thematic analysis. This was a significant oversight and it was unclear whether the design had been carefully considered prior to data collection.

Clarity of study aims and rigorousness of design.

Whereas the other studies made their aims very clear, which helped to orientate the reader within the research, Harker-Longton & Fish (2002), Duperouzel & Fish (2010) and Straiton et al (2013) failed to do this. Scourfield et al (2011)

identified “one of the main aims” (p. 779) as to “identify and analyse the discursive frames through which young people make sense of suicide and self-harm” (p. 799). They did not, however, list what the other aims might be and how they would fit alongside the identified aim. Harker-Longton & Fish (2002) and Straiton et al (2013), however, neglected to detail any kind of aim, making it harder to interpret their subsequent findings.

In terms of design, all studies gave a clear and relevant rationale for their design and methodology. The clear listing of inclusion criteria in Huband & Tantum (2004), Duperouzel & Fish, (2010) and Brown & Kimball, (2013) was very useful in understanding the links with existing literature and focused the research. The remaining studies would have benefitted from such a list. Morris et al (2015) listed criteria but these were confusing. Additionally, the authors listed further criteria for participation including being a parent to a child on the ‘child in need’ register or having engaged in life threatening self-harm, however, no justification was given for these criteria so it is hard to judge applicability of the subsequent conclusions drawn.

Duperouzel & Fish (2010) and Scourfield et al (2011) made use of a purposive sampling technique, which is common in, qualitative research but which can reduce the replicability of findings. The samples were recruited from a sub-group of patients from a forensic unit who were known to self-harm (Duperouzel & Fish,2010) and from a variety of sources but filtered to represent diversity of class, socioeconomic status, sexual identity and location (Scourfield et al, 2011). Scourfield et al (2011) put measures in place to reverse this effect by advertising for participants in a number of relevant places (colleges, youth clubs, social welfare organisations etc.) in the hope that a more varied sample would be captured but Duperouzel & Fish (2010) failed to do similar.

The samples recruited by Polk & Liss (2009) and Brown & Kimball (2013) might also be considered difficult to replicate. Polk & Liss (2009) only advertised on a self-injury support website. Although this will have presumably increased the likelihood of recruiting participants who self-harm, not everyone who self-harms accesses such sites. Therefore, the sample may have consisted of individuals with certain characteristics or views about their experience of self-harm. The ethos of the website was not described by the authors. Similarly, Brown & Kimball (2013) only advertised via a single university announcement so perhaps only captured participants with a certain level of education. This makes it difficult to view their findings as applicable to the larger self-harming population, yet was not considered as a limitation of their findings by the authors.

A final important consideration with respect to study design is the extent to which restrictions in the design may have impacted the results and subsequent conclusions drawn. Harker-Longton & Fish (2002) and Polk & Liss (2009), for example, allowed open discussion of participants' experience of the function of self-harm, allowing themes to emerge. Straiton et al (2013) also gave space for free text, asking participants to describe their selections made on a questionnaire regarding having previously hurt themselves. By contrast, Huband & Tantum (2004) made use of predetermined themes, thus unhelpfully restricting the range of possible findings.

Data collection and trustworthiness.

All qualitative studies with the exception of Harker-Longton & Fish (2002) and Straiton et al (2013) provided insufficient or incomplete descriptions of data collection.

Scourfield et al (2011) described the use of focus groups and interviews but not how these were structured nor who facilitated them. Huband & Tantum (2004)

mentioned that the same researcher completed all of the participant interviews but did not explain in what setting or under what circumstances these were carried out.

Morris et al (2015), Duperouzel & Fish (2010), Brown & Kimball (2013) and Horne & Csipke (2009) all neglected to detail whether the same researcher undertook interviews each time and so it is unclear how adherence to reflexive practice was ensured.

Although Harker-Longton & Fish (2002) did take these concepts into consideration, the interviews were carried out by a member of staff with whom the participant had a pre-existing (good) relationship. The benefits of this including helping to make the participant feel more at ease and facilitating more open expression of beliefs are admirable. However, the authors did not discuss whether the participant might feel discouraged from saying certain things to a member of staff (and therefore someone capable of influencing their care) that they might feel able to say to an independent interviewer. The other studies did not discuss researcher relationship to participants nor the potential impact of this on the trustworthiness of findings.

Only studies Harker-Longton & Fish (2002), Huband & Tantum (2004) and Straiton et al (2013) provided thorough explanations of how the research and issues regarding consent were described to the participants.

A strength of Morris et al (2015) was the involvement of a service user group in study planning from conception through to findings. This ensured that research decisions were informed by direct experience of what would be clinically relevant, adding weight to researcher interpretation of findings

A final strength was seen in Polk & Liss (2009) in which the authors took time to design their survey so that participants would only be able to complete the

questionnaire once. This eliminated the danger of repeat participants and increased replicability of findings and strength of conclusions. This choice was made in line with APA guidance for survey design (Kraut, Olson, Banaji, Bruckman, Cohen & Couper, 2004).

Transparency of analytical method and clarity of findings.

A limitation of Harker-Longton & Fish (2002) and Scourfield et al (2011) was that the data analysis was not clearly described. Conversely, this was well done in the remaining studies. Harker-Longton & Fish (2002) did not make clear the process by which themes were determined, leaving the reader unsure as to whether a standard method of coding was followed. Scourfield et al (2011) detailed some of its coding strategy but analysis and results were incoherently reported and the lack of an initially stated aim made it difficult to judge the relevance of the findings.

Scourfield et al (2011), Huband & Tantum (2004), Polk & Liss (2009) and Straiton et al (2013) all described the use of multiple coders for themes in their research ensuring increased possible replicability of the analysis and reported findings. Huband & Tantum (2004) also made use of participants in reviewing the codes and themes to ensure that they felt they captured their views accurately. This participant validation is something that would have been useful to be considered by the other authors too.

All qualitative studies made use of quotations in their findings to describe verbatim what participants had said about their views on the function of self-harm. This was useful in both understanding the themes presented by the authors and also grounding the research in real human experience.

All studies provided a good description of findings and modest conclusions. This is important because qualitative studies, by their very design, do not allow

researchers to suggest that their findings are generalisable to the larger population (in this case of people who self-harm) and so sweeping conclusions should not be made. Unfortunately, whereas most studies discussed some of the limitations of their design and the impact this might have had on the trustworthiness and replicability of their findings and conclusions, Harker-Longton & Fish (2002), Scourfield et al (2011), Duperouzel & Fish (2010) and Brown & Kimball (2013), failed to do so. With this in mind, their conclusions must be viewed with more caution.

Consideration of ethical issues.

Morris et al (2015) and Duperouzel & Fish (2010) did not consider the potential emotional impact of the research on participants as part of their consent seeking. Polk & Liss (2009) and Brown & Kimball (2013) did consider the benefits and risks to recruited participants but no steps were taken to promote wellbeing.

Conversely, Studies Scourfield et al (2011), Huband & Tantum (2004), Horne & Csipke (2009) and Straiton et al (2013) all put measures in place to help promote participant emotional wellbeing after identifying that participants might have been negatively affected by their research. This seemed especially pertinent for Horne & Csipke (2009) whom (due to the study design) were unable to seek ethical approval through official channels and had to put their own ethical procedures into place. Measures taken included placing a support worker at the interview site (Scourfield et al, 2011) giving advice about who to contact in the event of distress (Straiton et al, 2013) and structuring interviews in such a way that participants would not feel pressurised to discuss difficult memories (Huband & Tantum, 2004).

As well as the need to safeguard participants by conducting ethically sound research, there is also a potential impact on the trustworthiness of the results. If

participants do not feel emotionally safe or sufficiently supported to discuss potentially difficult topics for example, this might limit or alter what is shared with the researchers. This may therefore affect how the results can be interpreted and conclusions made.

Quality of Quantitative Studies

Suitability of quantitative approach.

In Klonsky & Glenn (2010) and Klonsky (2008), the use of a quantitative design was well thought out and appropriate in order to meet the aims of the studies. It might also have been interesting to include a semi-structured interview or free text boxes inviting participants to give their own accounts of the function of self-harm to identify themes that were not picked up by the questionnaires.

Population.

Both studies recruited participants (who had experience of self-harm) from a university undergraduate population that may not have been representative of the more general population of people who self-harm. Additionally, neither study reported in which country or countries the research was carried out in, making it hard to judge the potential range of applicability of findings.

A strength of Klonsky (2008) was the clear listing of inclusion criteria and accompanying rationale for these, which helped the reader understand the authors' thinking with regards the design of the study. Klonsky & Glenn (2010) neglected to do this making this more difficult. Without transparent inclusion criteria, it is difficult to draw clear conclusions.

Appropriateness of analyses.

The analyses detailed for both studies were appropriate considering the design and aims of the studies. The use of tables and figures improved clarity for the reader.

Cultural Context

It is also important to note that all of the studies reviewed were carried out in different countries (United Kingdom, United States and Norway) making it difficult to determine how well the findings could be generalised to the United Kingdom.

Summary and discussion of the functions of self-harm

The literature review was undertaken with the aim of establishing how self-harm might function in adults. The critique identified some excellent design considerations within the studies examined, but also some weaknesses. Despite the methodological limitations, however, and in accordance with the quality checklist used (NICE, 2012) the studies appeared to be sufficiently valid for robust conclusions to be drawn. Indeed, the agreement between studies (which made use of quantitative and a wide variety of qualitative methodologies) regarding the function of self-harm lends further weight to the validity of findings. This therefore means that the main question set by the review has been confidently answered (with the above caveats).

In terms of the findings, firstly, there was strong evidence found for the role of emotion regulation as a main function of self-harm. This was found across the board, even where there appeared to be secondary functions too.

Secondly, self-harm also appeared to function as a means of control: it gave participants more of a feeling of control over themselves, their bodies and the

situations they were in. This finding emerged clearly from the review and is linked to emotional regulation because this can also be seen as a form of control.

Thirdly, evidence for self-harm as a form of punishment was described by participants in one of two ways. When functioning as punishment of the self, this was predominantly because of a self-perceived personality slight such as feeling “dirty” (Harker-Longton & Fish, 2002, p. 143). When functioning as punishment for others, this appeared broader and might have been a reaction to a multitude of things, including, for example, turning angry feeling towards others: “I wanted someone, who had physically hurt me to understand how much pain I had inside me” (Straiton et al, 2013, p. 80).

Fourthly, there was less evidence for self-harm functioning as a way of communicating distress to others. It is unclear whether this was because it does not function in this way for most, or because of potential prejudice associated with admitting this. Indeed, Scourfield et al (2011) identified that self-harm was viewed as “attention-seeking” (p.779) when obvious to others (on exposed areas of skin for example) and that this had negative connotations. The finding that engaging in self-harm also made participants “(feel) different” (p. 129) from others in society potentially lends further support to this theory (Morris et al, 2015). The degree to which communicating distress serves as a function of self-harm therefore remains unclear and requires further investigation taking the potential role of prejudice into consideration.

Lastly, other possible functions of self-harm that emerged were: a distraction from suicidal or homicidal thoughts or actions, and self-harm increasing the connection between body and mind. These, however, have not been considered entirely trustworthy findings because each appeared to represent the experience of

specific individual participants rather than the broader population of people who self-harm.

Overall, the findings of this review therefore support those of Klonsky (2007) who found that the primary function of self-harm appeared to be emotional regulation. This is in line with Chapman et al (2006) whose Experiential Avoidance Model (EAM) suggested that self-harm is a way for individuals to cope with difficult emotions. The model proposes that self-harm is an avoidance of emotional distress because the individual is able to focus on the physical pain they are inflicting on themselves rather than the emotional distress they are feeling. In this sense, self-harm could also be considered a display of distress as suggested by Hawton, Saunders & O'Connor (2012) - emotional pain is being displayed in a physical way.

Bowlby's Attachment Theory (1969) suggests that those with poor attachment to the caregiver as a young child may develop difficulties with emotional regulation as an adult. Fonagy et al (2002) explain this by saying appropriate coping strategies were never modelled for the individual and so they develop their own, more destructive methods of managing

The findings here that suggest that self-harm may fulfil a number of additional functions, which vary from individual to individual and over time. These include, control (over the self or others) and punishment.

Some of the recommendations in Klonsky's (2006) earlier review had been addressed in more recent work including research into how self-harm regulates emotion and the use of community as well as inpatient samples. However, more detailed research into changes in affect associated with self-harm still need to be considered.

Implications

Implications for clinical practice

The findings have several important implications for clinical practice. First and foremost, there are a wide range of functions of self-harm identified here (which marry up with those also suggested in Klonsky's (2007) previous review). This highlights the need for clinicians to bear in mind that self-harm can fulfil different functions for different people and to assess this on an individual basis.

Particularly, clinicians should focus initial and long-term work on trying to understand the experience of the individual sitting in front of them, including the possible functions of self-harm for him or her in particular, rather than making a priori assumptions on the basis of psychological theory. This demonstrates the need for a thorough and collaborative formulation (Johnstone, 2013). Without this, attempts to understand individual experience might not be effective and so service-user experience of help-seeking compromised. It might also be difficult to build a strong therapeutic relationship, which is considered a major part of formulation and considered pivotal to positive change (Leach, 2005).

The need to consider the function of self-harm as an individual experience also has implications for how it is typically understood by psychiatry (and thus experienced by service-users accessing psychiatry services). Categorising self-harm as a symptom of mental illness such as schizophrenia (Haw et al, 2005) or of a personality disorder (Lieb, Zanarini, Schmahl, Linehan & Bohus, 2004) might discourage service users from seeking specific help for their self-harm. Some people might fear being given a label, perhaps, or others might feel that their self-harm is not merely a symptom of a disorder they have been diagnosed with, but instead a way of coping (Cresswell, 2005). Either way, these doubts might discourage help-seeking.

In addition, it is typical for questions asking service-users about self-harm clinically to take the form of a risk interview (Taylor, Hawton, Fortune & Kapur, 2009) asking practical questions such as how often someone self-harms or how severely. Such perfunctory questions may often lead to closed answers. This may therefore lead to potentially inadequate support being offered to the service user. Although assessing potential risk is of course important, this style of working may shut down possible future useful conversations about self-harm.

This form of communication between professionals and service-users seems particularly important in light of the most consistent findings of this review, namely that a primary function of self-harm appears to be to help regulate emotion (specifically reducing negative affect). Clinicians should try to collaboratively focus initial treatment goals on reducing negative affect rather than trying to reduce self-harm. Indeed, attempting to reduce or stop self-harm immediately may increase negative emotion or reduce a feeling of control (also seen as a function of self-harm), possibly resulting in an increase in self-harm and perhaps a subsequent difficulty in maintaining the therapeutic relationship (Leach, 2005).

This seems especially relevant in inpatient services where service-users who self-harm may be placed on close observations and/or have possessions removed from their personal space. Although the need to keep service users physically safe is of paramount importance, emotional safety is also vital. To remove the thing that gives the service user a sense of control (namely self-harm) may be extremely detrimental to their emotional safety. Services should therefore work towards devising interventions that promote both physical and emotional safety for service users.

Some services have implemented initiatives to try to achieve this balance such as The Drayton Park Crisis House (Cooke, 2015) where staff will give service-

users clean blades with which to self-harm if their other coping mechanisms are not working. They have found that “the knowledge that they (the residents) could come for a blade meant that self-harming behaviour reduced” and the service-users had more power over their own decisions. This therefore suggests that a less restrictive way of managing self-harm within residential services can have positive effects.

Indeed, this initiative seems an excellent example of ‘least restrictive practice’. This is a term regularly heard (particularly in inpatient services) as the gold standard services would like to achieve (Bachrach, 1980). However, it is something that remains difficult when working within a medical model that conceptualises self-harm as a risk symptom to be managed and restrictive practices as necessary safety measures (James, Stewart & Bowers, 2012).

The need for supportive and non-judgemental therapeutic relationships with clients clearly fits hand in hand with this. This is because least restrictive practice must be built on some element of trust both ways between service user and clinician. An enhanced level of trust would hopefully have the knock-on effect of allowing service-users to disclose some of their more difficult emotions to clinicians, rather than self-harming as a first choice of emotional regulation. Perhaps exploring emotions could usefully be a primary focus of treatment. At the same time, clinicians should be aware that discussion of said emotions might initially increase the likelihood of increased self-harm by the very nature of the functional connection.

Alongside the need to improve staff reactions to service-user self-harm within residential settings, there are also implications in the community. People who self-harm and live in the community might come into contact with frontline services such as A&E or the ambulance service for first aid treatment. Service-user accounts have detailed displeasure with such services including experiencing judgement and

discrimination from staff, (Cresswell, 2005). This has included, for example, negative comments from staff or waiting times being longer than they should be considering the severity of the injury because they were self-inflicted. It is clear that this is a highly unacceptable way to treat people who self-harm. Perhaps a lack of understanding of the reasons why people self-harm and the function(s) it has for them, are partly to blame for these negative reactions.

Training for both frontline and mental health clinicians about the functions of self-harm and the need to be non-judgemental and non-discriminatory seem of paramount importance. This could be co-coordinated by (ex) service users to enhance authenticity and emphasise the need for change.

As a separate but related consideration, clinicians should also be aware of the influence of social prejudice on their care of service users. Even though it is deemed socially unacceptable to self-harm (Urquhart-Law et al, 2008) the societal 'truth' may not reflect how the individual sees the world. If the individual is experiencing self-harm as a negative in their lives, it might still be the most effective coping strategy they have in their current circumstances (Pembroke, 1998). It is for these reasons that clinician value judgements must be sufficiently bracketed and the focus must remain on the function of self-harm for the individual. This seems especially important when considering self-esteem of the individual. It makes sense that having to manage prejudice on top of an existing difficult experience might have a detrimental effect on self-esteem.

In terms of current psychological treatments typically offered for those who self-harm, Dialectical Behaviour Therapy (DBT) is popular. It aims to validate service-user experience of self-harm but also help them to initiate change (reducing frequency and severity) (Swales, Heard & Williams, 2000). DBT aims to facilitate

service-users to learn techniques to regulate and manage intense emotions, which may otherwise result in self-harm. It would seem important to continue to offer DBT as an intervention for self-harm considering the findings of this review and Klonsky's (2006) earlier review that suggest emotional regulation is a key function of self-harm for many individuals. A clinical psychologist might take the role of providing DBT delivery training to other healthcare professionals to maximise provision.

A final point to consider (as with all psychological intervention work) is the system around the individual with whom the clinician is working. Attempting to reduce self-harm might not be possible for someone living with extreme stress or in a very challenging environment and indeed they might not want to if it is helping them to cope. In these circumstances, it may be useful to focus more on harm-reduction techniques instead of prevention (Guttridge, 2010).

Implications for research

The current review suggests numerous useful avenues for future research into the functions of self-harm. It appears that qualitative research in particular provides a richness of data. This seems important with self-harm research firstly because it is an under-researched field. Secondly, because it appears to be highly individualistic in terms of function and so it seems remiss not to directly ask for participant open opinions. With this in mind, it would be useful for research to work towards developing a standardised 'function of self-harm' measure. This should include a section for individual comment to be considered together by the client and clinician. Currently there are several self-harm measures, but these ask service-users to fit themselves into boxes representing pre-conceived ideas about self-harm function rather than asking about individual experience. A measure with additional free text

boxes would hopefully enhance service assessment of individuals and selection of appropriate treatment.

Future research should also focus on emotional regulation as a function of self-harm and the components of this (which types of emotions most often need regulating for example). This is because this was such a strong and consistent finding within this review.

Research into self-harm in adults often considers it as a symptom of a mental illness such as schizophrenia (Haw et al, 2005) or as a feature of personality disorder (typically BPD) (Lieb et al, 2004) rather than a communication of distress or a common and potentially understandable human experience. Viewing self-harm as a symptom in this way is sometimes seen as dismissive and can prevent clinicians from talking to service users to try to understand why they self-harm and what function it serves for them (Cresswell, 2005). If experienced in this way, this might prevent improvement of understanding of self-harm clinically or promote awareness and compassion societally. Future research into self-harm in the context of diagnoses aside from BPD and schizophrenia might be helpful in understanding it as more of a human behaviour that serves a particular function and less of a 'symptom'.

There also seems to be a need for an empirically developed model to explain the different possible functions of self-harm (according to people who self-harm) and how these might interplay. Such a model might further inform empirical understanding of self-harm function, increase societal awareness and could also be used clinically in collaborative work with service users to help formulate their difficulties. However, caution on the part of the clinician would still need to be exercised to ensure the model fits with the individual's experience, rather than the experience being fitted into the model.

Conclusions

This review aimed to explore and understand the functions of self-harm in adults. Although the findings must be interpreted in the light of design limitations, they did suggest there are several main categories of self-harm function. These were emotional regulation, control, punishment (of the self or others) and less consistently expression of distress. This is in line with a previous review of the literature concerning the function of self-harm (Klonksy, 2007).

These findings have potential clinical and research implications. Clinical implications include prioritising individualistic care, formulation and intervention, improved therapeutic alliance, consideration of the categorisation of self-harm in healthcare, improving staff attitudes and the delivery of co-produced training in healthcare to improve the health seeking experience. Research implications include: a future focus on further understanding emotional regulation as a function of self-harm, consideration of improvements to self-harm measures, the impact of diagnostic labels in promoting awareness and compassion societally and the need for a model featuring the varied functions of self-harm.

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HOLLY TETT BSc MSc

Section B

“It’s the way I cope”

**How do people who hear voices and also self-harm
understand the relationship between the two?**

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MAY 2017

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Aims

The study aimed to develop a theory of the possible links between voice-hearing and self-harm.

Method

Twelve semi-structured interviews were conducted with participants living in the community and in a secure forensic setting. All participants had experience of both voice-hearing and self-harm. A grounded theory of possible links was developed from participants' accounts of their experiences.

Results

All participants described self-harm as way of coping with negative voices and of regulating painful emotions. Some described it as a response to a fear of judgement from others, as a form of control or as a means of seeking help.

Conclusions

The results suggest that there are numerous links between voice-hearing and self-harm. Predominantly, self-harm seems to function as a way to cope with individual voice-hearing experience. Help should focus on triggers to distress and ways to cope. Training for healthcare staff could usefully be provided by service users, focusing on the importance of being non-judgemental. Future research could examine tactile and visual experiences in relation to self-harm too, clinician perspectives on the links between voice-hearing and self-harm, and service user perspectives on the emotional availability of clinicians.

Key words: Self-harm; hearing-voices; command hallucinations; auditory hallucinations; adults; links

Introduction

There is very little theoretical or empirical literature exploring possible relationships between self-harm and voice-hearing nor are there prevalence rates regarding their co-occurrence. Traditional systems of diagnosis including The Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013) deal with these phenomena separately. Self-harm is often seen as relating to a personality disorder (Gratz & Tull, 2012) and voice-hearing as a feature of psychotic illness (Holzer, Willis & Halfon, 2001).

It is presumably for this reason that empirical research has tended not to consider them together either. The exception to this is found in literature that links self-harm with ‘command hallucinations’ (Rogers, Watt, Gray, McCulloch & Gournay, 2002) where self-harm appears to be considered as, or as arising from, a symptom of psychotic disorder.

Despite the lack of specific research, there are indications that there might be a significant overlap. Challis, Nielsen, Harris & Large (2013) found for example, that one in ten people who were diagnosed with initial episode psychosis also self-harmed during this time.

The heavy reliance on a medical model to understand both voice-hearing and self-harm (Beecher, 2009; Haw, Hawton, Houston & Townsend, 2001) could in part be responsible for the lack of in-depth research asking individuals directly about their experiences and whether they believe they inter-relate. Self-harm and voice-hearing appear to have been seen as symptoms of separate disorders with different underlying pathologies. These are personality disorder (Andover, Pepper, Ryabchenko, Orrico & Gibb, 2005) and psychotic mental illness (Pogue-Gelle, and Harrow, 1984)

respectively. The possible links between them have therefore not been empirically considered.

A reason for the lack of research asking people directly about their experiences may lie in clinician belief about particular ‘disorders’. People with a diagnosis of psychotic disorder have often been considered to lack insight into their experience (Reddy, 2015), and those with a diagnosis of personality disorder have sometimes been seen as un-cooperative or deceitful (Saunders, Goodwin & Rogers, 2015). In attempting to understand possible links between the two phenomena, however, asking those affected seems a sensible place to start.

Defining self-harm

Self-harm is perhaps the most commonly used term in the UK to describe causing deliberate injury to one’s bodily tissue. For this reason, and because it is also the term most used by people who themselves self-harm (Cresswell, 2005), it will be the term used throughout this study. Other terms include self-mutilation, self-injury and deliberate self-harm in addition to terms which describe the type of self-harm such as cutting (Klonsky, 2008).

A distinction has increasingly been made between suicidal and non-suicidal self-harm {Non Suicidal Self-Injury or NSSI} (Glenn & Klonsky, 2013). As a recent addition to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), NSSI can be diagnosed when individuals, amongst other criteria, have caused “5 or more days of intentional self-inflicted damage to the surface of the body without suicidal intent within the last year”. There was some disagreement about the usefulness of making this distinction because although much self-harm is not suicidal in intent, research has suggested that there is a strong link

between self-harm and later suicide attempts (Stanley, Gameroff, Venezia-Michalsen & Mann, 2001). Additionally, giving self-harm a diagnostic label was the cause of much contention for some, who argued that self-harm was not a mental disorder but instead a reaction to or way of coping with distress (Horne & Cspike, 2009).

Current understanding of self-harm

Research has suggested that self-harm might function in various ways including as a relief from emotional pain (Horne & Cspike, 2009), as punishment to the self (Klonsky, 2007), as an escape from emotional distress by dissociation (Chapman, Gratz & Brown, 2006) and as a form of control over thoughts or a situation (Kemperman, Russ & Shearin, 1997). Regardless of specific function, most authors agree that self-harm is most often a response to emotional distress of some kind.

Increasingly, self-harm has been seen as part of a particular disorder, namely personality disorder, and specifically BPD: Borderline Personality Disorder (Gratz & Gunderson, 2006). Although self-harm in the context of BPD is sometimes seen as a response to distress (Nock & Mendes, 2008), it has also been framed as ‘manipulative’ and as a way of gaining attention from others in an unnecessary or exaggerated way (Commons-Treloar & Lewis, 2009). In some cases, this has led individuals to feel that they must self-harm severely in order to be taken seriously by professionals and non-professionals alike and to show that they are in ‘real’ emotional pain (Boriril, Snow, Medlicott, Teers & Paton, 2005). This reaction is perhaps understandable but also worrying, suggesting that professionals are failing to understand and support service users with their experiences.

Repeatedly, research in this area has found that those who self-harm complain of poor responses from staff. Examples include waiting until the end of the queue in A&E (regardless of medically determined priority) and being spoken to with contempt because wounds are self-inflicted (Palmer, Blackwell & Strevens, 2007). It has been suggested that some negative responses of healthcare staff could be explained by lack of understanding about why people self-harm, personal prejudice, or distress due to working with people who have self-harmed and are distressed themselves (McKay & Barrowclough, 2005).

Defining voice-hearing

The most commonly accepted term for hearing a voice or voices that others cannot perceive is 'hearing voices' or 'voice-hearing' (McCarthy-Jones, 2012). The medical term 'hallucination' (Chadwick & Birchwood, 1994) is seen by some as unnecessarily pathologising (Gagg, 2002) and will not be used here. Voice-hearing appears to be experienced differently by everyone. Some describe hearing one voice, for example, and some many. Some people recognise the voices, others do not. Beavan & Read (2010) suggest that voice hearing can be experienced as one or more voices being heard that are separate from one's own thoughts. The voice(s) might talk directly to the individual or comment on their behaviour or the behaviour of others. Sometimes voices might threaten the hearer and/or command them to carry out certain actions. Alternatively, the voice(s) might be less direct and experienced as background noise.

Some individuals have described accompanying visions, smells and tactile experiences that are felt as sensations on the surface of the skin or within the body but for which there is no obvious external stimulus (Mueser, Bellack & Brady, 1990).

In some cultures voice-hearing has also been linked to spiritual experiences and can be viewed as a great honour (Davies, Griffin & Vice, 2001) however, this is less common in the United Kingdom.

Current understanding of voice-hearing

As outlined above, within Western psychiatry, voice-hearing has usually been considered a symptom of a psychotic disorder such as schizophrenia and described in medical terms as ‘auditory hallucinations’ (Liddle, 1987). However, some have suggested that conceptualising voices in this way masks the heterogeneity of the experience. They have suggested that it is inappropriate in non-psychiatric settings or for people who hear voices but cope well or view the experience positively and do not come into contact with mental health services (Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014).

Viewing voice-hearing merely as a symptom of psychosis might not just be seen as reductionist, but also a factor that potentially contributes to the stigma surrounding hearing voices in society. A study by Furnham & Rees (1998) for example, found that members of the public associated those with a diagnosis of schizophrenia as amoral and/or dangerous members of society. The ramifications of these beliefs are far reaching and might be extremely distressing for people living with voices. Pembroke (2014) spoke about how changing language such as ‘auditory hallucination’ to ‘voice-hearing’ can be freeing because it speaks of an experience without suggesting its origin. This therefore allows for individual experiences to be explored more easily rather than clustering them together.

Voice-hearers have detailed both positive and negative relationships with their voices (Jackson, Hayward & Cooke, 2011). The bulk of research has focused on negative relationships with voices and the complexities of (Sorrell, Hayward & Meddings, 2010).

Gaps in knowledge

As outlined above, self-harm and voice-hearing have often been considered separately and little research or theory has attempted to account for the link between them. Where research has been undertaken, the focus has been primarily on self-harm in response to command hallucinations (Gerlock, Buccheri, Buffum, Trygstad & Dowling, 2010). As such, the possible relationships between the experiences have not been fully considered.

When explored in relation to other diagnoses (for example BPD) self-harm is often viewed as a coping mechanism and as a way of managing difficult emotion (Christian & McCabe, 2011). However, these explanations have not featured in accounts of the possible relationship between self-harm and voice-hearing. This seems remiss considering the overlap between different psychiatric diagnoses (for example, social withdrawal and low mood are both considered features of both psychosis and depression (DSM-5, American Psychiatric Association, 2013)) and in view of the distress often associated with the experience of voice hearing (Orr, Kellehear, Armari, Pearson & Holmes, 2013).

Romme & Escher (1994) suggested that the difference between those who did and did not require healthcare within the voice hearing community was accounted for by the relationship between the individual and their voices. A negative relationship might evoke more distress, therefore requiring psychological support. However, it is

conceivable that many other factors might also come into play here such as previous experience with services, cultural background and existing support systems.

Research has also neglected to consider how stigma associated with voice-hearing (Wong et al, 2009) might negatively impact the self-esteem of the voice hearer. The link between low self-esteem and self-harm has been regularly noted (Fliege, Lee, Grimm & Klapp, 2009) so further exploration of this in relation to voice hearing would be helpful.

Relatedly, some service users accounts have detailed dissatisfaction with healthcare worker attitudes towards self-harm in particular (Pembroke, 2006) and also towards voice-hearing (Yoko, Takahiro, Noohisa , Tajiū & Naoyuki, 2015) but research into how this might affect people individually is lacking. These negative experiences may also account, in part for the lack of information regarding population prevalence rates for people who self-harm and hear voices. This is because fear of experiencing prejudice may impact help-seeking behaviour or the desire to take part in research (Pembroke,2006).

A further consideration is the potential link between both self-harm and voice-hearing with trauma. Research has suggested that self-harm might function for some as a form of dissociation from difficult emotions related to previous trauma (focusing on physical pain rather than emotional pain) (Chapman et al, 2006). The notion that voices might also be borne as a way of protecting the self from traumatic memories has also been previously explored. Steel (2015) suggests that voices develop as an unconscious way of focusing the thoughts away from the trauma and might be considered protective in that sense, although many do report negative associations with voices too. There might be similarities in terms of how both voice hearing and self-harm might act as a mechanism for individuals to dissociate themselves from

memories and negative feelings associated with past trauma. It is therefore conceivable that this might account for the shared experience some individuals have of voice-hearing and self-harm although this has not yet been considered empirically.

Rationale behind and aims of this study

The current study addresses the gap in the existing literature regarding the relationship between self-harm and voice-hearing. It aims to explore possible functions that self-harm might fulfil for voice-hearers other than appeasing command hallucinations. It is possible that these might include, for example, reducing distress or increasing feelings of control over a situation, which are examples of suggested functions of self-harm in other contexts (Klonsky, 2006).

The lack of previous research addressing this question may be related to the dominance of the medical model in both theory and services. This tends to view voice hearing as a symptom of psychosis to be treated with antipsychotic medication, and self-harm as a feature of 'personality disorder', thus allowing little room for the understanding of how these two experiences might interact.

It is hoped that an improved understanding might have useful implications for clinical practice and help improve the experience of service users who interact with healthcare services for support with voices and/or self-harm.

Methodology

Overall Design

This study made use of a qualitative design (Grounded Theory), which allows an in-depth exploration into participants' individual accounts of their experience.

Grounded Theory methodology in particular, lends itself to studying phenomena where there is little pre-existing theory (Charmaz, 2014; Urquhart, 2013). The researcher, after completing an in-depth analysis of the findings, can develop a theoretical model grounded in individual accounts of experience.

Epistemological Stance

This research adopted a social constructionist epistemological stance. I was aware that their interpretation of the results was partly shaped by co-constructed knowledge (Yardley, 2000). With this in mind, a reflexive stance was adopted and pre-existing beliefs and assumptions were acknowledged throughout the research process. This approach seemed particularly pertinent with the voice-hearing population focused on here, whose experiences have often been trivialised or stigmatised (Wong et al, 2009).

Participants

Participants were recruited from the community and from a medium secure forensic unit in the hope of hearing from a range of different people. Community based participants included those who had pre-existing and existing contact with mental health services, as well as those who had never been in contact. There were 12 participants whose demographic information is displayed in Table 1.

Table 1: Participant demographics

Participant	Participant Gender	Participant Age	Participant Ethnicity
1	Female	22	White Irish
2	Male	32	Black British
3	Female	47	White British
4	Female	53	White British
5	Male	53	Black British
6	Male	40	Asian
7	Not disclosed	Not disclosed	Not disclosed
8	Male	34	Black Caribbean
9	Male	65	Black British
10	Female	37	Black British
11	Female	27	White Other
12	Male	53	White British

All participants met the inclusion criteria listed (Table 2).

Table 2: Study inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Individuals who have experienced at least one 6 month period during which they have both heard voices and self-harmed	Individuals who have not experienced at least one 6 month period during which they have both heard voices and self-harmed
Individuals over the age of 18	Individuals under the age of 18
Individuals deemed capacious to consent to take part in the study (for inpatient sample this to be judged by treating team)	Individuals not deemed capacious to consent
Individuals able to sit alone with the researcher for the duration of the interview(s)	Individuals on 1:1 observations (within hospital)

Ethical Assurance

This research adhered to the British Psychological Society (BPS) code of ethics and conduct (BPS, 2014). Ethical approval for the study was granted by the National Research Ethics Committee (Bloomsbury Branch – see Appendix B) and the NHS Health Research Authority (see Appendix C). Further site approval was given by the Research and Dissemination Department of the NHS Trust (see Appendix D) from which the inpatients were recruited.

Following interviews and prior to data analysis, participants were anonymised using a random number generator.

Procedure

Recruitment and data collection.

Recruitment and data collection took place between October 2016 and February 2017. In the forensic unit the rationale for the research and inclusion criteria were presented to service users in the community meetings on each ward with an opportunity to ask questions of the researcher. Information sheets (see Appendix E) giving more detail about the study were accessible on the ward and participants were asked to approach the researcher directly or leave a message with the ward staff if they wanted to take part. Potential participants (i.e. those who initiated contact with the researcher) were given a further copy of the consent form (see Appendix F) to look at and a week to consider their participation. They were also reminded that their treating team would need to be made aware of their participation: all participants agreed to this. The treating teams were contacted to ensure they felt that participants had the capacity to consent to take part and considered their mental state to be

sufficiently stable. All team opinions were favourable. The information sheet and consent forms were independently reviewed and evaluated by a service user review team whose suggestions for improvement were incorporated.

Participants from the community were recruited online by means of advertising the study website (see Appendix G for a link to the website) on self-harm and voice-hearing support forums and websites. Participants were invited to register their interest in taking part by contacting the researcher via the study email address. Some potential participants were in contact with mental health services or under the care of their GP with regard to their voice-hearing or self-harm experience. In these cases and with their agreement, the researcher contacted the relevant professional to inform them of their client's participation in the study.

All participants were given a week to read the information sheet and consent form and make a decision about their participation. Six potential participants were not invited to take part in the study because they failed to meet the inclusion criteria. They were thanked for their interest and the reasons for not asking them to participate (in the context of the aims of the study) were briefly explained.

The information sheet (Appendix E) detailed the rationale and purpose of the study, the ethical considerations, researcher expectations of participants and their right to withdraw from the study.

The lead researcher conducted all interviews. The inpatient interviews were conducted in private interview rooms on the ward. Whilst this was not ideal (there was some background noise from the corridor and some rooms may have had negative connotations for participants) for practical reasons (i.e. restrictions operating

within the unit) it was the best option available. Interviews with non-inpatient participants took place in a quiet public place of participants' choosing (examples included coffee shops, private rooms at drop-in centres and libraries).

All interviews were recorded on a digital recorder (of which the participants were aware) and started with a recap of the main points detailed on the information sheet. Informed written consent was obtained and participants were encouraged to ask for a break or to stop if necessary. Participants were also asked to detail how they might communicate distress to the researcher if needed and a short debrief was conducted after each interview.

The interviews used a semi-structured interview schedule (see Appendix H) designed by the researcher in consultation with a service user mentor who oversaw all aspects of the research. It was also piloted with a colleague but no changes were deemed necessary. The schedule consisted of 13 questions: most of these were broad as suggested by Charmaz (2014) in order not to lead participants into answering in a certain way and to allow for free expression. The semi-structured format allowed for questions to be adapted slightly in response to participants' answers and for additional questions to be asked where appropriate in the hope of producing rich data.

Steps were taken to ensure the personal safety of the participants and the researcher in addition to those discussed above. Inclusive in the information sheet was contact details for participants to speak to a clinical psychologist or to the Samaritans should they feel distressed following the interview. Interviewer safety was ensured on the forensic unit by way of personal alarm, communication with ward staff regarding interview location and duration and 'in the moment' risk assessment skills of the interviewer. With regards interviews taking place in the community, the researcher

informed the lead supervisor of the location and time of each interview and checked in after the interview.

Method of analysis.

Constructivist grounded theory methodology was followed during analysis (Charmaz, 2014). All interviews were transcribed verbatim from the recording and the decision was made to code each line-by-line. This is because the interviews represented a wide range of experiences and line-by-line coding allows for detailed engagement with participant responses and less chance of coding being influenced by researcher opinion (Charmaz, 2014). An example of a coded transcript can be seen in Appendix I. Glaser (1978) suggests coding using gerunds to ensure that codes are action focused and not just descriptive of what was said and this method was used here. One transcript was initially coded by a colleague, allowing the researcher to reflect on their immersion with the data. Fortunately, the codes were identified similarly, however, the researcher's codes tended to use more emotive language. This was perhaps reflective of their invested position as lead researcher and also because they had conducted the interviews in person.

Data collection followed an iterative process as proposed by Charmaz (2014). The first three interviews were coded initially (as above). General themes identified allowed for the interview questions to be adapted to include questions related to these themes. This ensured that the process of data collection was organised around participant responses and not researcher preference.

Following initial coding, the data was analysed using focused coding and employing the constant comparative method (Glaser & Strauss, 1967). This ensured

that the data was being repeatedly reviewed and links identified so that coding was trustworthy and less likely to be influenced by researcher prior bias in thinking. Focused coding identified 86 focused codes (see Appendix J), categories, and sub-categories were developed from grouping these (see Appendix K for a visual representation of this process). Data collection continued until theoretical sufficiency (Dey, 1999) was deemed to have been reached. Unfortunately, it was not possible to reach theoretical saturation of data within the time constraints of the study.

Memos were used throughout the analytic process to increase depth of thought in relation to the codes, to consider the relationships between codes and to draw attention to emerging theory (Glaser, 1988). An example of a memo can be seen in Appendix L. The use of focused coding and memos in combination, allowed for the development of thematic categories and sub-categories that were representative of emerging patterns and allowed for a theoretical model to be produced.

Quality Assurance

The research process was monitored and evaluated using appropriate research guidelines for qualitative research (Yardley, 2000). These can be seen in Appendix M. As mentioned above, both a service user research group and the service user mentor reviewed the initial interview schedule. A self-reflective research journal was also kept throughout the process (see Appendix N for an extract) and a bracketing interview was conducted part way through analysis in order to bracket ideas and assumptions that might have otherwise influenced the interpretation of the data (Charmaz, 2014). The supervisors of this research were experienced with grounded theory methodology and one supervisor checked the coding of a transcript.

Additionally, the focused coding structure and subsequent categories and model were independently reviewed by two colleagues with little knowledge of the area and positive feedback was given.

Results

Overview of the findings

Participants described four main links between voice-hearing and self-harm: the role of self-harm in emotional regulation, self-harm as a response to a fear of judgement from others regarding voice-hearing, the role of control in voice-hearing and self-harm in relation to help-seeking for voices. An over-arching link that encompassed each of these was something that was identified by all participants: self-harm as a way of coping with voice-hearing. It is important to note that despite the fact the findings can be grouped into these categories, within each category there were varied individual experiences.

It is also crucial to note that participants only identified a link between hearing negative voices and self-harm. Although some participants did report hearing positive voices as well (something that is a well documented experience (Jackson, Hayward & Cooke, 2011)), they did not report links between positive voices and self-harm.

Participants described a wide range of negative voices, including those that called them names, threatened them directly, threatened those they cared about or told them to do unpleasant things.

The fact that participants linked hearing negative voices and self-harm emphasises the fact that they viewed hearing negative voices as something that

warranted the need for coping strategies. Self-harm was one such coping strategy. This is a new finding that does not fit with the focus of previous research that has suggested that self-harm is linked to hearing voices only as a response to a command hallucination (Rogers, Watt, Gray, McCulloch & Gournay, 2002).

Detailed description of findings

Self-harm as a response to a fear of judgement from others regarding voice-hearing.

Some participants described experiencing prejudice and judgement from others regarding their voice-hearing:

I know there's stigma and prejudice around voice-hearing. I mean the first time I was admitted to hospital and I lost all my friends and stuff that was part of the case. 'Cause if I'd gone to prison...and you come out of prison and people think that's cool and that's respectful. Even if you murdered someone you get a lot of respect even though that's an awful thing to do. But if you come out of hospital they treat you like you're a freak show (Participant 4)

The experience of feeling judged led to distress and/or the decision not to seek help resulting in a need for emotional regulation:

I've been so judged for hearing voices, called crazy and mental and stuff, even by nurses in the past and that makes you feel awful so I just think, why would I want to ask for help when everyone thinks I'm mad (Participant 3)

Significantly, participants had experienced more prejudice and judgement with regard to voice-hearing than to self-harm. Some explained that they self-harmed in an

attempt to cope with negative voices and therefore conceal their voice-hearing experience to avoid further judgement.

If I cut they just deal with the practical stuff of stitching me up so they don't ask questions about the voices. I feel far less judged...whereas where I've let them in about my voices before...well you can see that look on their faces; they just think I'm crazy. I guess with self-harm, like everyone has pushed their nails into their palms when they're worried or whatever haven't they? So this is just a more extreme version of that...so yeah, people get it more

(Participant 1)

The role of control in voice-hearing and self-harm.

Another theme that emerged was one of control: some participants described feeling controlled by negative powerful voices:

They are in control. The bad voices are always in control of what I think and what I do even though I try to fight them (Participant 2)

These participants explained that if they self-harmed to appease the voices then the voices would disappear temporarily, leading to improved affect:

They tell me to cut so I cut. It shuts them up for a bit and I can just rest a bit in peace (Participant 7)

Others described a more circular pattern whereby they would self-harm in an attempt to appease the voices but this would not be successful, resulting in the voices demanding further self-harm and this repeating in a cycle until the voices were finally satisfied:

It probably has in a certain way because my self-harm...when I used to self-harm and the voices were saying, 'go on, do it deeper, do it deeper. You aint done it deep enough, you aint done it deep enough. (Participant 10)

In contrast, other participants described self-harm as a way of taking control back from the voices. Here the decision to self-harm was the participant's alone and a way they could resist or defy the voices. This then enabled participants to feel as though they had reclaimed some control over their own lives and bodies. This regaining of control fed back into the same loop where participants experienced a break from the voices and subsequent improved affect:

It's sort of my way of getting the control back. This is my body and I can do what I want with it (Participant 1)

The role of self-harm as emotional regulation.

One of the main findings was the role of **self-harm as a form of emotional regulation**. This was something discussed by all participants in some form. Participants described experiencing painful emotional reactions to negative voices, which self-harm helped to regulate:

I think it has helped me cope with some of the emotions, the guilt and the fear (Participant 5)

The painful emotions described by participants varied, but were predominantly distress, fear and shame. Participants described voices having a distressing impact:

The voices can feel so intense. It can be so intense and distressing. It can feel like a migraine and a regular headache at the same time. Self-harm helps to calm all that down (Participant 11)

Evoking fear:

When the bad voices start...it's just terrifying. That's the only way I can describe it. But when I cut, it grounds me (Participant 1)

Resulting in the individual feeling ashamed of their experience:

They're always putting me down, the bad voices. It doesn't do much for your self-worth, you know? (Participant 2)

In each case, participants described self-harm helping to reduce the intensity of the distressing emotions (improved affect).

Self-harm as a way of coping with hearing voices.

The main finding that emerged from all interviews was that participants saw self-harm as a way of coping with the experience of negative voice-hearing. As above, self-harm helped some participants regulate their emotions, some cope with the fear of judgement from others and some to cope with controlling voices:

It's the way I cope and that's that. If people knew what it really felt like to live with these voices every day then they wouldn't be so keen for me to stop cutting (Participant 2)

Self-harm as a way of seeking help.

In terms of seeking peer support, participants described peers and family members encouraging professional help-seeking more quickly when participants disclosed they had been self-harming.

My boyfriend actually started taking it seriously when saw the scars. That's when he wanted me to get help, not with any of the other stuff (Participant 2)

For some participants self-harm was a way of seeking help from others (either professionals, or friends and family). Participants described self-harm and especially severe self-harm being taken seriously by others. They suggested that help was more likely to be given for both voice-hearing and self-harm if distress was communicated via severe self-harm:

Because I used to self-harm in such an extreme way a lot of them used to take me seriously. I used to make a big hole in my arm and all that (Participant 9)

Self-harm as a way of protecting the self and others from further harm.

Some participants described having self-harmed as an alternative to hurting others during an intense situation.

If I get violent or become aggressive I think about self-harming. Probably because I don't like taking my feelings out on other people...turn it in on myself (Participant 10)

For other participants, self-harm was an alternative to suicide, a way of protecting themselves and staying alive:

Desperation definitely, and often there's a lot of fear as well. Not of the self-harm but what might happen if I don't self-harm. I'd be thinking about ways to die (Participant 11)

Summary of findings

Participants' accounts of the relationship between voice hearing and self-harm were multi-faceted and multi-layered (see fig 1). The role of self-harm as emotional regulation, as a response to judgement from others and as a method of control were all strong findings. It is clear that not all findings would apply to everyone who has the dual experience of voice-hearing and self-harm. However, the strong link seen between the different sections (namely, self-harming as a coping mechanism) unifies the experiences. It is possible that the experience of some might differ dependent on situation or time rather than remaining static. Alternatively, the themes identified here might simply represent different people's experiences.

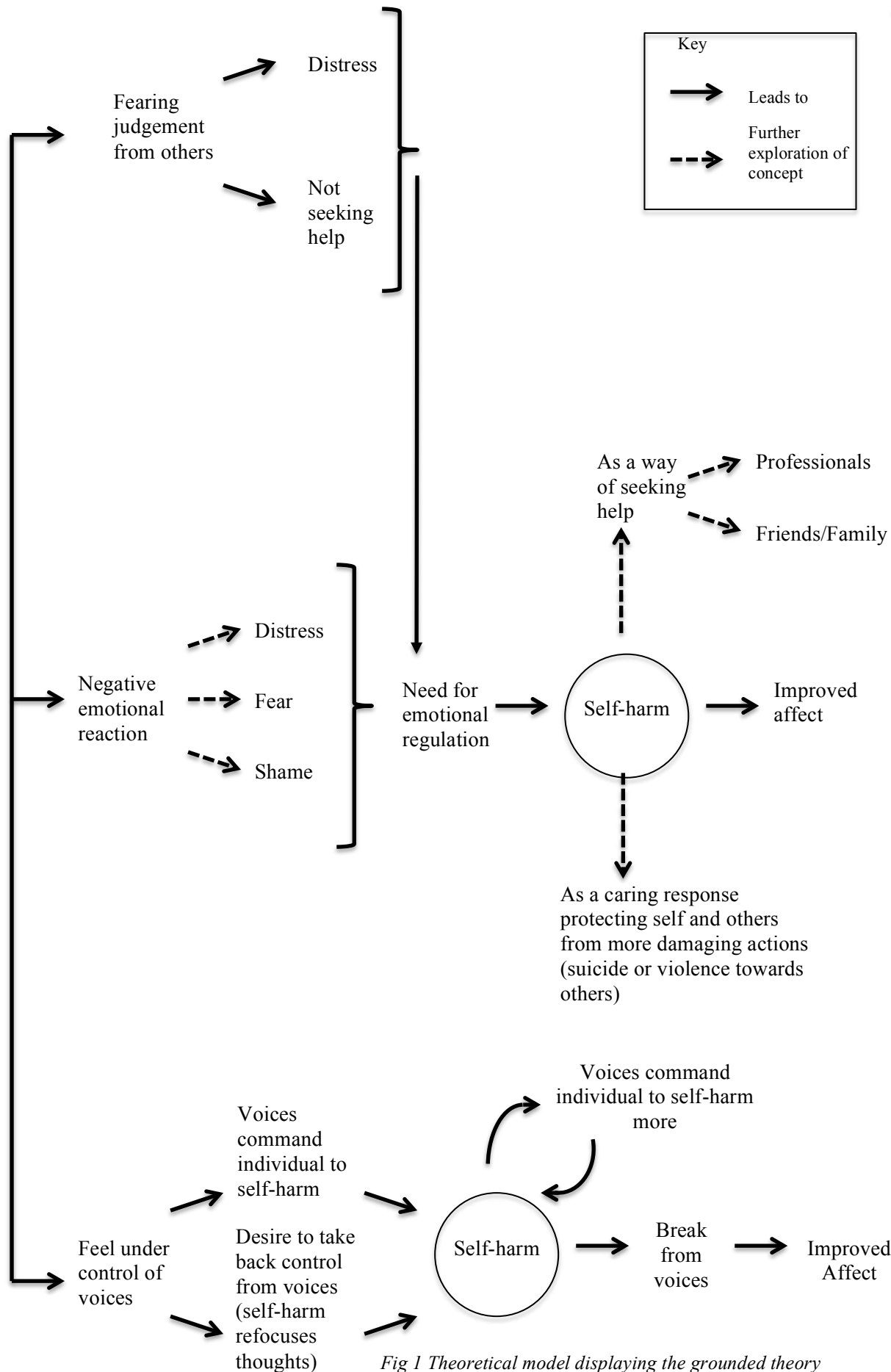
The Model

The model presented in Figure 1 (below) was developed as one way of organising the above findings, capturing participants' expressed understanding of the link between voice-hearing and self-harm.

The model flows out from the left hand side where an individual hearing negative voices is depicted. This results in either the individual fearing judgement from others, having a negative emotional reaction or feeling under control of the voices. In each of these three possible responses to initially hearing the negative voices, there is more than one path that can be taken, dependent on individual experience. Each pathway leads to the individual self-harming and how this then

affects them in the immediate short-term. As discussed above, all aspects of the model are encompassed by the theory that self-harm serves as a coping strategy, regardless of personal experience.

HEARING NEGATIVE VOICES



SELF-HARM AS A COPING STRATEGY

Fig 1 Theoretical model displaying the grounded theory

Discussion

Overview of findings

By means of a constructivist grounded theory analysis, this study has highlighted some key processes involved in the relationship between voice-hearing and self-harm.

The main overarching finding was that participants viewed self-harm as a way of coping with the emotional distress provoked by hearing negative voices.

Within the overall domain of coping, several individual functions of self-harm were identified, including the role of self-harm in emotional regulation, self-harm as a response to a fear of judgement from others regarding voice hearing, self-harm as a way of managing controlling voices and self-harm as a means of help-seeking.

Participants identified that the varied experiences necessitating self-harm as a coping strategy (as listed above) might vary for different people. Alternatively, struggling to cope might be dependent on situational factors such as the person's wellbeing at the time of hearing the negative voice, their environment and/or the content of the voices.

Links to previous theory and research

Self-harm as a way of coping with hearing voices.

A significant main finding was that self-harm was a coping response to emotional distress provoked by the experience of hearing negative voices. To the author's knowledge, this is a new finding: this is the first empirical study to address

this question. It is, however, consistent with literature regarding the role of distress in self-harm more generally (Horne & Csipke, 2009; Christian & McCabe, 2011).

Self-harm as a form of emotional regulation.

Another main finding was that self-harm functioned as a form of emotional regulation when negative voices were very distressing. Again, this is something that has not been previously considered empirically. This seems remiss considering the high levels of distress reported by some voice hearers (Dillon & Hornstein, 2013). Additionally, the evidence that has been found for self-harm functioning as emotional regulation elsewhere (in relation to depression for example, Skegg, 2010) lends further weight to this.

Self-harm as a form of emotional regulation when hearing negative voices can also be considered in terms of Zubin & Spring's (1997) Stress-Vulnerability Model. Hearing negative voices on a regular basis can be considered a 'vulnerability' for that person. So perhaps the stress of hearing a particularly negative voice repeatedly or in conjunction with other stressful life events is enough to 'trigger' the individual to self-harm in order to cope. Self-harm is acting as a regulator for the stress caused by repeatedly hearing negative voices.

Self-harm as a response to a fear of judgement from others.

A second major finding was participants fearing negative judgement from others for voice-hearing and the role of self-harm in limiting this. Participants made it clear that both self-harm and voice-hearing can evoke judgement from others and that this might cause distress and/or prevent them from seeking help. It was found though, that perceived judgement associated with voice-hearing was greater than that

associated with self-harm. In some cases, individuals described self-harm as a way of managing their voices so as not to have to share their voice-hearing experience with others and feel judged.

The concept of judgement or discrimination against those in emotional distress is echoed in much mental health research (Wahl, 1999). Campaigns such as Time to Talk (Mind & Rethink Mental Illness, 2017) have been created to try to raise awareness, promote understanding and to tackle such discrimination. These types of campaigns do, however, rely on a medical explanation of experiences such as hearing voices, naming the experience as an illness that can be likened to a physical ailment such as breaking a bone. Although this attempts to promote compassion, it still pathologises those who hear voices, rather than identifying voice-hearing as a human experience like any other.

It has been well documented that people who self-harm have experienced prejudice from society (Hodgson, 2004) and healthcare professionals alike (Cooke, 2013; Warm, Murray & Fox, 2002). This highlights how significantly some of the participants in this study felt prejudiced against for hearing voices.

It is conceivable that voice-hearing attracts so much prejudice because it is often viewed societally as a symptom of a mental illness (schizophrenia for example). Mental illness has been found to have many negative connotations in society. Furnham & Rees (1998) for example, found that lay-people associated people with schizophrenia diagnoses with characteristics including amorality and dangerousness.

The role of control in voice-hearing and self-harm.

Another key finding was the role of self-harm in mediating control between participants and their voices. Two differing functions were described.

Some participants described feeling under the control of the voices and self-harming because the voices commanded them to do so. In some cases this appeased the voices, resulting in a break from them and improved affect. This is in line with previous research attributing self-harm in voice-hearers to compliance with ‘command hallucinations’ (Liddle, 1987).

Other participants said that obeying once rarely satisfied the voices, which then encouraged further or more severe self-harm. This circular pattern could sometimes repeat many times until the voices were satisfied. Few studies have considered this idea, however, requiring further research to understand how this might work.

Some participants described the role of control differently. Namely, how sometimes they used self-harm as a way of controlling the voices rather than the voices controlling them. Here participants felt that the negative voices were monopolising their thoughts, allowing little room for other things to feature. Self-harm was a way of focusing the thoughts away from the voices and thus gaining some control back.

The role of taking control in self-harm in relation to experiences of depression is well documented (Skegg, 2010). Thought should be given as to why this has not been considered with voice-hearing. It is possible that the stigmatised view of voice-hearers as dangerous and violent (Furnham and Rees, 1998) leads others to see their self-harm as an expression of violence. This contrasts with the sympathy often

afforded to people with diagnoses of depression, whose self-harm might be considered non-threatening and an expression of distress.

Self-harm in relation to help seeking.

Some participants described self-harm as a way of seeking help for voice-hearing (either from professionals, peers or both). Participants described their distress being taken more seriously by others when in the form of self-harm. Perhaps a visual representation of distress (self-harm) is easier for others to comprehend than a verbal description of internal distress (hearing voices).

This explanation contradicts some previous research that has suggests that self-harmers are ‘attention-seeking’ or using self-harm to ‘manipulate’ others. These terms are often attributed to those who self-harm and have also been given a diagnosis of BPD (Gratz & Gunderson, 2006).

Clinical Implications

The study findings have implications for those working clinically with people who hear voices and self-harm.

Firstly, the variety of potential links between voice-hearing and self-harm found in this sample alone, indicates how individual experiences are. It is therefore important to ask service-users about how they view the link between their voices and their self-harm. They should be regarded as experts of their own experience before theoretical assumptions are made by clinicians. Psychology supported but service-user led ‘Hearing Voices’ groups might help to form positive relationships between service users and professionals that promote recovery.

With this in mind, the findings presented here did suggest that self-harm is a way of coping with negative voice-hearing. This was something expressed by all participants, regardless of other individual differences. It therefore seems pertinent that clinical work should focus first on what features of a person's voices are causing most distress. Clinicians should then focus on understanding how self-harm improves coping and collaboratively develop treatment plans to learn further coping skills.

Secondly, the significance of self-harm as a form of emotional regulation and as a method of coping in relation to hearing negative voices should not be underestimated. Thought should be given to the potentially detrimental effects of encouraging service-users to stop self-harming immediately, thus removing a coping mechanism. These results therefore have further implications for considering self-harm as a method of harm-minimisation (be that psychological harm: hearing distressing voices or physical harm: e.g., attempts to take one's own life) (Pembroke, 2000). When formulating with a client using CBT for psychosis for example, therapists might discuss with service-users about whether they consider their self-harm a protective factor in the first instance because this might be the case for some. This has further implications for service risk management plans on inpatient wards, for example. Policies such as removing potential objects with which service users could self-harm or placing people on one-to-one observations are some of the current ways self-harm risk is managed by healthcare workers. Service user accounts have described these types of restrictive practices as causing more distress in some cases. Conversely, services such as Drayton Park Crisis House (Cooke, 2015) where service users are able to ask staff for a clean blade with which to self-harm if their other coping methods are not working have had good results. Service users have given

positive reports about increased autonomy and incidence of self-harm has also reduced in this service.

Additionally, services could promote peer support groups to enable more service users to seek support from others with similar experiences. Research has provided evidence for the effectiveness of peer support, arguing that it might be useful in a way that cannot be replicated by professional services (Repper & Carter, 2011).

Thirdly, the role of actual and perceived prejudice from others in relation to voice-hearing was something that participants had experienced from professionals and from society in general. It therefore seems imperative that appropriate training is given to healthcare staff so that they can work effectively and compassionately with service users who require help. This includes frontline staff such as A&E, emergency services and administrative staff within mental health services.

Appropriate training for mental health professionals focusing on how to ask service users about their voices and how they affect them would also seem useful and perhaps this could be co-led by service user representatives. In addition, psychology led reflective practice groups for other members of the multi-disciplinary team could help promote compassion and generate thinking about the best way to offer care.

Fourthly, and linked with the above, mental health professionals have a role to play in challenging discrimination both in the work place and more widely, showing their support for media campaigns tackling prejudice. Part of this work might involve challenging the concept of diagnosis as a way of understanding voice-hearing and self-harm. Previous research has suggested that service-users might experience

professionals differently dependent on their diagnosis (Cooke, 2013) which is clear discrimination (whether deliberate or not). Moving away from the use of more reductionist medical terms such as BPD or psychosis to explain these experiences will hopefully help to reduce this type of prejudice.

Strengths and limitations of the design

Strengths.

This is the first study to directly ask people who both hear voices and self-harm about their understanding of the link between those two experiences, and to produce a model grounded in their accounts. This is particularly important in a context where voice-hearers often complain that their own views as to the nature and function of their experiences can be ignored by professionals (Yoko, 2015).

The main findings, namely that self-harm was used as a form of emotional regulation and a coping strategy by participants when hearing negative voices lends weight to new clinical thinking. In particular, moving away from the use of somewhat simplistic medical diagnoses to explain voice-hearing and self-harm and focusing on individual experience may help to provide a better service.

A constructivist approach was taken with this research. Thinking in this way reminded the researcher that the findings and model presented above are embedded within their relationship to the data and that others may have interpreted the data differently. With this in mind, steps were taken to analyse emerging beliefs and assumptions before, during and after the research in order to be aware of what the researcher was personally adding to the interpretation.

Despite these quality checks, it is still important to consider the findings within the framework they were analysed in and recognise that they do not put forward a ‘truth’ but rather an interpretation.

Limitations.

A limitation of this research was that the community sample of participants were only recruited via online advertisements on self-harm and voice-hearing support forums and websites. It is conceivable that people who use such forums have certain characteristics in common, and that the findings may therefore not account for the experiences of those who do not.

Similarly, triangulation could have been achieved by interviewing and comparing participants from different countries. This would have been particularly interesting in thinking about self-harm feeling less judged by participants than hearing voices. There might have been differences between countries regarding how those who hear voices are viewed and therefore whether the same links to self-harm were found. Unfortunately this was not possible here due to time constraints.

This study focused on the experience of voice-hearing in relation to self-harm, however, participants did identify other non-shared perceptions alongside voices. These might also have been relevant in explaining the link between voice-hearing and self-harm if experienced in conjunction with voices. These included tactile and visual experiences:

Or even seeing, you know, bugs crawling under my skin, you know, the fear is definitely a big one (Participant 11)

It would be interesting to compare the findings from this research with future research asking participants about the latter experiences in depth too.

A further limitation of the results was that the analysis was not verified by participants to check for potential discrepancies in interpretation which is recommended (Charmaz, 2014). This was due to a lack of time.

A final limitation was a more practical one but something that might have had an impact on how able participants felt to share their experiences. The design of the study necessitated using face-to-face interviews and recording these using a digital recorder. Some participants mentioned that being recorded made them feel anxious or paranoid. It is possible that some potential participants may not have volunteered for the study for this reason, and that there may be systematic differences between these individuals and the volunteers. Alternatively, some participants may have modified their responses or held back from voicing some of their thoughts due to their concerns. This raises issues about whether or not people experiencing paranoia may feel alienated from some qualitative research (because of the emphasis on recording) and therefore be potentially underrepresented by findings.

A different method of interviewing such as using an instant messaging or a video chat platform might have made this easier because participants would not have been constantly looking at the digital recorder whilst speaking.

Implications for future research

As above, it would be interesting for future research to also consider other non-shared perceptions such as tactile or visual experiences and whether these are involved with the link between voice-hearing and self-harm as well.

This study found a link between judgement from others for voice-hearing and subsequent self-harm in some participants. Although judgment came from a variety of sources, this highlights the importance of clinicians' attitudes: if service users are able to discuss their voice-hearing experiences without fear of judgement, they are perhaps less likely to need to self-harm in order to conceal their experience. Research into clinician views about those who hear voices would be very useful to identify possible prejudices ingrained within healthcare culture.

Additionally, research into clinicians views regarding the link between voice-hearing and self-harm would provide a useful comparison with this study. In seeing how well (or not) clinician perceptions and participants accounts of the experience marry up, steps can be taken to improve service provision. Larger scale research of this type would improve generalisability of findings.

A further area of interest for research would be service user perceptions of the emotional availability of clinicians and what aspects of services they find helpful or not. This study found that in some cases, participants' self-harm functioned as a way of seeking help for their experience of hearing negative voices. Perhaps therefore clinicians are not making themselves openly available to discuss service users' experience of voices, making service users feel they must resort to other ways to communicate distress and thus seek help.

It would also be interesting to conduct similar research but with an adolescent population in order to see whether expressed experience was different across age groups. This is especially because most research into self-harm is carried out with adolescent participants (Hawton, Harris, Hill & Simpson, 2003) . However, there is limited research into a possible link between self-harm and voice-hearing in

adolescents, just as there is in adults. This could have implications for working effectively with first episode psychosis.

A final consideration for future research is whether the model put forward here could also be tested quantitatively to further examine its robustness. This could take the form of a structured self-report questionnaire incorporating questions regarding participant experience of the different sections of the model. It would allow for the model to be tested on larger number of participants.

Conclusions

This study aimed to hear from participants with experience of voice-hearing and self-harm about whether they identified a link between the two and if so how they conceptualised this.

All participants said that voice-hearing and self-harm were linked and described self-harm as a way of coping with negative voices. They identified that self-harm might be required as emotional regulation, as a response to a fear of judgement from others regarding hearing voices, as a way of seeking control when hearing voices and in relation to help-seeking for hearing voices.

Several possible implications were identified for both future research and clinical practice. In terms of research, there is a need for studies looking at how tactile and visual experiences might also relate to self-harm. A better understanding of how clinicians view the link between voice-hearing and self-harm and how well this marries with service users accounts would also be useful.

Clinically, particular focus should be on acknowledging that self-harm might be a way of coping with negative voices and being sensitive to this when working with service-users to try to minimise harm. Making use of peer support across diagnostic categories might also have positive outcomes. Finally, emphasising the responsibility of clinicians to understand individual experience of voice-hearing and self-harm rather than attempting to fit service-user experience into pre-determined theoretical boxes.

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SECTION C – Appendices of supporting material

Appendix A – NICE guidelines quality appraisal checklist

Checklist

Study identification: Include author, title, reference, year of publication		
Guidance topic:	Key research question/aim:	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: <ul style="list-style-type: none"> • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question? 	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: <ul style="list-style-type: none"> • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed? 	Clear Unclear Mixed	Comments:
Study design		

<p>3. How defensible/rigorous is the research design/methodology?</p> <p>For example:</p> <ul style="list-style-type: none"> • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified? 	<p>Defensible</p> <p>Indefensible</p> <p>Not sure</p>	<p>Comments:</p>
<p>Data collection</p>		
<p>4. How well was the data collection carried out?</p> <p>For example:</p> <ul style="list-style-type: none"> • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic? 	<p>Appropriately</p> <p>Inappropriately</p> <p>Not sure/inadequately reported</p>	<p>Comments:</p>
<p>Trustworthiness</p>		
<p>5. Is the role of the researcher clearly described?</p> <p>For example:</p> <ul style="list-style-type: none"> • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants? 	<p>Clearly described</p> <p>Unclear</p> <p>Not described</p>	<p>Comments:</p>

<p>6. Is the context clearly described?</p> <p>For example:</p> <ul style="list-style-type: none"> • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered 	<p>Clear</p> <p>Unclear</p> <p>Not sure</p>	<p>Comments:</p>
<p>7. Were the methods reliable?</p> <p>For example:</p> <ul style="list-style-type: none"> • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to? 	<p>Reliable</p> <p>Unreliable</p> <p>Not sure</p>	<p>Comments:</p>
<p>Analysis</p>		
<p>8. Is the data analysis sufficiently rigorous?</p> <p>For example:</p> <ul style="list-style-type: none"> • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data? 	<p>Rigorous</p> <p>Not rigorous</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>9. Is the data 'rich'?</p> <p>For example:</p>	<p>Rich</p> <p>Poor</p>	<p>Comments:</p>

<ul style="list-style-type: none"> • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites? 	<p>Not sure/not reported</p>	
<p>10. Is the analysis reliable?</p> <p>For example:</p> <ul style="list-style-type: none"> • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored? 	<p>Reliable</p> <p>Unreliable</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>11. Are the findings convincing?</p> <p>For example:</p> <ul style="list-style-type: none"> • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent? 	<p>Convincing</p> <p>Not convincing</p> <p>Not sure</p>	<p>Comments:</p>
<p>12. Are the findings relevant to the aims of the study?</p>	<p>Relevant</p> <p>Irrelevant</p> <p>Partially relevant</p>	<p>Comments:</p>
<p>13. Conclusions</p>	<p>Adequate</p>	<p>Comments:</p>

<p>For example:</p> <ul style="list-style-type: none"> • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? <p>Is there adequate discussion of any limitations encountered?</p>	<p>Inadequate</p> <p>Not sure</p>	
<p>Ethics</p>		
<p>14. How clear and coherent is the reporting of ethics?</p> <p>For example:</p> <ul style="list-style-type: none"> • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee? 	<p>Appropriate</p> <p>Inappropriate</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>Overall assessment</p>		
<p>As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)</p>	<p>++</p> <p>+</p> <p>-</p>	<p>Comments:</p>

Appendix B – Ethics Approval Letter

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Appendix C – HRA Approval Letter

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Appendix D - R&D approval letter

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Appendix E – Information sheet



VERSION 3
19/09/2016
IRAS No: 193648

Information about the research

How do those who hear voices and also self-harm understand the relationship between the two?

Hello. My name is Holly and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.

Part 1 of this information sheet tells you the purpose of this study and what will happen if you take part.

Part 2 gives you more detailed information about the conduct of the study.

PART ONE

What is the purpose of the study?

The purpose of this study is to speak with people who both hear voices and self-harm and whether or not they believe these two things are connected in some way. There has been research that has looked at these two things before but it has mainly looked at people who hurt themselves because the voice tells them to. This may be the case for many people but this study aims to see if there are other links between self-harm and hearing voices too.

This study is being part supervised by a service user mentor who has lived experience of both self-harm and hearing voices.

Why have I been invited?

You have been invited to take part in this study because of one of the following reasons:

- You are member of a hearing voices support group and you also self-harm
- You are a member of a self-harm support group and you also hear voices
- You are currently receiving hospital treatment in a mental health unit and you both self-harm and hear voices

In order to take part in this study:

- You will have experienced at least one 6 month period during which you have self-harmed and heard voices.
- It does not matter if this is current or was in the past.

Do I have to take part?

The decision on whether or not to take part in the study is entirely yours. If you do decide you would like to participate then I will ask you to sign a consent form to confirm this. Before or after signing the consent form you have the right to withdraw from the study at any point and you do not have to provide a reason for this. The decision to withdraw will not affect the standard of care you receive from mental health services (if you are currently under the care of services) nor prevent you from remaining a member of a group or network.

What will happen to me if I take part?

If you agree to take part we will meet for an interview where I will ask you some questions about your experience of hearing voices and self-harm. This will be recorded with a Dictaphone but not videoed. It should last between 30 and 60 minutes. At the end of the interview I will ask you if you are happy for me to contact you again if I have any further questions. It is your choice whether or not you agree to this but I will only ask you to meet a maximum of twice during a one year period.

The findings from the research will take some time to produce and write up but I will ask you if you would like a copy of the report when it is finished and if so I will send this to you.

Expenses and payments

You will be offered a £10 high street voucher to thank you for your time and participation in the study.

What will I have to do?

You will be asked some questions about your experience of hearing voices and of self-harming.

Some of the questions may feel personal in nature as they will ask you to draw on your own memories of periods of your life which may have been distressing or perhaps are still distressing.

It will be possible to stop during the interview for a break if you want to or to finish the interview at a later date if this would be easier.

As mentioned above, the interviews will be recorded with a dictaphone and you will not have to write anything down or bring anything with you to the interview.

What are the possible disadvantages and risks of taking part?

Due to the fact the interview will be asking questions about voice hearing and self-harm, some people may find the questions personal in nature and may feel uncomfortable disclosing information. However, it is entirely up to you what you

wish to disclose and to what degree.

The questions asked may also remind participants of difficult memories which may cause distress or they might touch upon things which participants are currently experiencing as distressing.

It is also conceivable that talking about voice hearing may increase the intensity of existing voices or that talking about self-harm may increase the desire to self-harm although this will obviously be specific to the individual and we would ask that participants be mindful of these possibilities when deciding whether or not to take part in the study.

What are the possible benefits of taking part?

This study is not intended to be used as a treatment or therapy for participants, however, participants may find it personally helpful or interesting to talk through their experiences.

The information that we get from this study will hopefully help us to better understand the experience of people who hear voices and also self-harm. This in turn may help improve the support provided by professionals working with individuals in the future.

What if there is a problem?

Any concerns or complaints about how you were dealt with during the study or any possible harm you might suffer will be addressed. This is explained further in Part 2 of this sheet.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART TWO

What will happen if I don't want to carry on with the study?

If you do not wish continue with the interview or the study at any point you may withdraw. This includes changing your mind about being contacted again (in the event I ask you to answer further questions).

If you do withdraw we would like to use the information you have provided up until the point you choose to withdraw. However, if you are certain you would like all your data to be removed from the study we will do so and destroy any recordings.

You will be offered emotional support (the opportunity to discuss your participation with a Psychologist) if you would like to.

What if there is a problem?

If you have found the interview emotionally distressing and would like to speak confidentially to a Psychologist you may contact one of the supervisors of this project, Anne Cooke. Her contact details are listed below. Of course you can also discuss things with people you are close to or with a member of your treating team (if in contact with mental health services). Alternatively you might want to contact The Samaritans who provide confidential support by means of telephone drop in, text or email. Their contact details are also listed below:

Anne Cooke: 0333 011 7073

The Samaritans provide confidential support for people in distress or despair:

Tel: 116 123 (free phone)

Website: www.samaritans.org

Email: jo@samaritans.org

Drop-in: Some local branches offer drop in services during the daytime

If you would like to make a complaint about the study or your experience as a participant of the study then a complaints procedure is in place in order for you to do so.

Complaints

If you have a complaint you can address this with myself in the first instance and I will endeavour to resolve it with you either at the time or as soon as possible afterwards. I will give you timescale within which I will contact you. My contact details are:

Email: hearingvoicesselfharmresearch@gmail.com

If you remain unhappy with my response and would like to take your complaint further you can contact the Research Director at Salomons University who will investigate this for you. His contact details are:

Paul Camic
Research Director
Salomons Centre for Applied Psychology
Canterbury Christ Church University
Tunbridge Wells, Kent TN3 0TF

Email: paul.camic@canterbury.ac.uk

You can, of course, contact Paul in the first instance instead of myself if necessary.

Will my taking part in this study be kept confidential?

Your information will be kept strictly confidential. Any personally identifiable information (e.g your consent form) will be securely stored in a locked filing cabinet and destroyed at the end of the study in September 2017.

As above, your interview will be recorded using a dictaphone. This will then be transferred onto an encrypted memory stick and the original deleted. Your recording will be saved using a participant number which will be randomly assigned to you and therefore your data will be anonymised.

After the data has been analysed, the recordings will be transferred to a password protected CD and stored securely at Salomons University Campus for a period of 10 years after which point they will be securely destroyed. All data from the encrypted stick will be deleted.

Your data will only be used for this study.

Involvement of the Care Co-ordinator / Treating Team / GP

If you are currently an inpatient on a mental health ward then your care co-ordinator and treating team will be made aware of your participation in this study. However, the information you provide will not be communicated to them. The only exception to this is if you divulge that you have plans to harm yourself or others. The same will apply if you are currently under mental health services within the community (your key worker/GP will be made aware of your participation).

What will happen to the results of the research study?

When the study has been completed and written up it will be submitted for publication in a Journal. You may request a copy of the findings and full study report by either letting me know at the time of interview or by contacting me on:

Email: hearingvoicesselfharmresearch.com

Anonymised quotations from the interviews may be used in the published report.

Who is organising and funding the research?

This research is being funded by Canterbury Christ Church University. I am the lead researcher and responsible for organising the study with support from my supervisors who are based at the University and a service user mentor.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Bloomsbury Research Ethics Committee.

Seeing as this study is recruiting participants from both the NHS and the general community it has also been reviewed by Canterbury Christ Church ethics panel.

This information sheet is yours to keep and you will also be given a copy of your signed consent form for your records.

Further information and contact details

If you would like any further information about this research please contact me on:

Email: hearingvoicesselfharmresearch.com

You may also wish to discuss your participation in the study with friends, family or a member of your care team if you are involved with one.

Appendix F - Consent form

VERSION 3
19/09/2016
IRAS No: 193648

Study Number:
Participant Identification Number for this study:

CONSENT FORM

Title of Project: How do those who hear voices and also self-harm understand the relationship between the two?

Name of Researcher: Holly Tett

Please initial box

1. I confirm that I have read and understand the information sheet dated 19/09/2016 (version: 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. 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.

3. I agree to my GP/ key worker/ treating team being informed of my participation in the study (only for those currently in contact with mental health services) [if applicable].

4. I agree to the audio recording of the interview and understand that this will be kept safe until which time as it is securely destroyed.

5. I agree that anonymous quotes from my interview may be used in published reports of the study findings.

6. I agree to take part in the above study.

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix G – Hyperlink to recruitment website

<https://www.hearingvoicesandselfharm.com/>

Appendix H – Interview schedule



VERSION 1
23/03/2016

Initial Interview Schedule

Information for participants prior to interview

- Introductions
- Reminder that it's ok to ask for a break during the interview or to end the interview early if you need to. How will you let me know if you're feeling upset or overwhelmed? I may offer you a break if you appear upset or overwhelmed.
- Reminder of how the interview will be recorded (by dictaphone) and the approximated length of the interview (30-60 minutes)
- Confidentiality of information and exceptions to this
- What sort of things will I ask?
- You are welcome to ask me to clarify or repeat a question
- What will happen at the end of the interview (ask if possible to re-contact)
- Participation voucher to be given at the end

Post-interview debrief session

- How did you find the interview? Was anything worrying or upsetting?
- How to seek support or make a complaint
- How to contact the researcher with any further questions
- Are you happy to be re-contacted with further questions?
- Would you like to be contacted with the results of the study? If so take contact details
- Providing participants with high street voucher if desired

Question themes

Due to the fact this research will make use of Grounded Theory, the questions below are quite broad in nature. Further and more specific questions will be developed as the study progresses.

1. Did you experience voice hearing or self-harm first?
2. Do you think there is a link between your voice hearing and self-harm?
3. Do you have periods where your voices make you want to self-harm more? (Prompts: for example when they are more intense or less intense? When certain voices are more present?)

4. Do you have periods where your self-harm makes your voices more intense or less intense? (Prompts: for example do they comment on your self-harm?)
5. Does self-harm keep you to gain control over your voices or do the voices help you to gain control over your self-harm?
6. What emotions/feelings/situations do you associate with self-harm?
7. What emotions/feelings/situations do you associate with hearing voices?
8. Does self-harm help you to cope with hearing voices?
9. Do you feel able to speak to others about your voice hearing and self-harm? (Prompts: Is it easier to talk about one more than the other? Why do you think this is?)
10. Have you sought support for your experience of hearing voices? (Prompts: How did this go? What wasn't done/said/offered which you would have found helpful?)
11. Have you sought support for your experience of self-harm? (Prompts: How did this go? What wasn't done/said/offered which you would have found helpful?)
12. Is there anything else you think it would be useful for me to know?
13. Do you have any questions for me?

Prompts for participants

- How do you mean?
- What impact did that have on you?
- Could you tell me a bit more about that?
- Could you explain what you mean by that?
- How do you manage that?
- Could you give me an example of that?

Appendix I – Example of a coded transcript

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Appendix J – List of focused codes

1. Self-harm resulting in life or death
2. Self-harm being the lesser of two evils
3. Self-harm acting as a substitute, unable to hurt the voices but can hurt the self
4. Claiming there is a link between hearing voices and self-harm
5. Linking an increase in voice intensity with an increase in distress
6. Explaining that sometimes self-harm can be a spontaneous reaction to distress caused by the voices
7. Self-harm as a way of protecting others from the self
8. Self-harm acting as self-care
9. Recognising the existence of prejudice around self-harm from professionals
10. Lack of consistency in staff responses to self-harm
11. Perceiving stigma around hearing voices to be greater than stigma around self-harm
12. Feeling that voice hearing is surrounded by heavy prejudice
13. Finding it difficult to talk about experience of hearing voices and self-harm
14. Identifying that stigma prevents people from talking to others about their experience
15. Describing prejudice as a contributor to distress
16. Isolation contributing to negative voices
17. Associating being in hospital as a result of self-harm/hearing voices experience with being judged by others
18. Experiencing the prejudice against those who hear voices and those who self-harm as feeling of the same intensity
19. Challenging the labels associated with hearing voices

20. Claiming that often people who hear voices are perceived as dangerous by the public but those who self-harm are not
21. Attributing negative judgement from others as their inability to understand the experience
22. Describing an increase in voice severity as a precursor to increased likelihood of self-harm
23. Seeking peer support for coping with experience
24. Seeking multiple sources of help
25. Describing being offered practical support for self-harm more often than emotional support
26. Help more effective when compassionate and non-judgemental
27. Extreme self-harm acting as a way of seeking help for hearing voices
28. Self-harm acting as a 'gateway' to get required help for hearing voices
29. Voices are described as being powerful
30. Voices taking away autonomy
31. Voices disturbing attempts to get help for self-ham
32. Negative voices associated with stopping the person from enjoying things
33. Experiencing negative voices as unsettling
34. Self-harm being a form of control
35. Self-harming to appease voices
36. Self-harm as a way of gaining control over the voices
37. Identifying that lack of task or focus increases likelihood or presence of voices
38. Self-harm being something personal
39. Voices instructing one to self-harm
40. Voices continuing to talk when person is self-harming

41. Voices encouraging greater injury
42. Describing an increase in voice severity as a precursor to increased likelihood of self-harm
43. Attributing self-harm to survival
44. Self-harm acting as anti-suicide
45. Experiencing negative voices as disturbing
46. Negative voices described as threatening
47. Attributing voices to extreme negative emotion
48. Identifying negative emotions fuelling the desire to self-harm
49. Describing a strong connection between not coping/being stressed and increased voice-hearing and self-harm
50. Self-harm acting as an escape from negative thoughts
51. Self-harm acting as a release/break from the voices
52. Self-harm acting as a release/break from negative emotions associated with hearing voices
53. Self-harm described as improving mood
54. Self-harm acting as a release of tension
55. Self-harm acting as a distraction from hearing voices
56. Associating voices with feeling to blame for something
57. Associating hearing voices with not being good enough
58. Hearing voices negatively affecting self-worth
59. Hearing voices associated with feeling ashamed
60. Experiencing some voices as pleasant
61. Self-harm as a coping mechanism
62. Self-harm quietening the voices

63. Self-harm being a reaction to stress
64. Self-harm improving clarity of thinking
65. Identifying that the positive effects of self-harm are time limited
66. Denying that self-harm increases voice intensity
67. Describing self-harm as multi-faceted in relation to voice-hearing
68. Identifying that everyone has an individual experience

**Appendix K - Table showing development of categories and sub-categories from
focused codes**

Category	Subcategory	Focused Codes
Self-harm as a way of coping with voice-hearing	Self-harm improving affect	<ul style="list-style-type: none"> - Self-harm as a coping mechanism - Self-harm quietening the voices - Self-harm being a reaction to stress - Self-harm improving clarity of thinking - Identifying that the positive effects of self-harm are time limited - Denying that self-harm increases voice intensity
	Everyone has an individual experience	<ul style="list-style-type: none"> - Describing self-harm as multi-faceted in relation to voice-hearing - Identifying that everyone has an individual experience
	Self-harm as a reaction to voice-hearing	<ul style="list-style-type: none"> - Self-harm acting as a substitute, unable to hurt the voices but can hurt the self - Claiming there is a link between hearing voices and self-harm - Linking an increase in voice intensity with an increase in distress - Explaining that sometimes self-harm can be a spontaneous reaction to distress caused by the voices
	Self-harm as a caring response	<ul style="list-style-type: none"> - Self-harm as a way of protecting others from the self - Self-harm acting as self-care
Self-harm as a way of managing the prejudice associated with voice-hearing	Prejudice from professionals	<ul style="list-style-type: none"> - Recognising the existence of prejudice around self-harm from professionals - Lack of consistency in staff responses to self-harm
	Stigma surrounding voice-hearing greater than stigma surrounding self-harm	<ul style="list-style-type: none"> - Perceiving stigma around hearing voices to be greater than stigma around self-harm - Feeling that voice hearing is

	<p>Stigma stopping people seeking help for distress</p> <p>Intense experience of stigma with voices and self-harm</p> <p>Negative labels given to people who hear voices</p>	<p>surrounded by heavy prejudice</p> <ul style="list-style-type: none"> - Finding it difficult to talk about experience of hearing voices and self-harm - Identifying that stigma prevents people from talking to others about their experience - Describing prejudice as a contributor to distress - Isolation contributing to negative voices - Associating being in hospital as a result of self-harm/hearing voices experience with being judged by others <p>- Experiencing the prejudice against those who hear voices and those who self-harm as feeling of the same intensity</p> <ul style="list-style-type: none"> - Challenging the labels associated with hearing voices - Claiming that often people who hear voices are perceived as dangerous by the public but those who self-harm are not - Attributing negative judgement from others as their inability to understand the experience
<p>Self-harm as a way of regulating emotions associated with hearing negative voices</p>	<p>Negative voices evoking extreme negative emotional reaction</p> <p>Self-harm improving affect</p>	<ul style="list-style-type: none"> - Attributing voices to extreme negative emotion - Identifying negative emotions fuelling the desire to self-harm - Describing a strong connection between not coping/being stressed and increased voice-hearing and self-harm <ul style="list-style-type: none"> - Self-harm acting as an escape from negative thoughts - Self-harm acting as a release/break from the voices - Self-harm acting as a release/break from negative emotions associated with hearing voices - Self-harm described as improving mood - Self-harm acting as a release of tension - Self-harm acting as a distraction from hearing voices

	<p>Hearing negative voices negatively affecting self-esteem</p> <p>Self-harm as a survival strategy</p> <p>Voices evoking fear</p>	<ul style="list-style-type: none"> - Associating voices with feeling to blame for something - Associating hearing voices with not being good enough - Hearing voices negatively affecting self-worth - Hearing voices associated with feeling ashamed - Attributing self-harm to survival - Self-harm as anti-suicide - Self-harm resulting in life of death - Self-harm being the lesser of two evils - Experiencing negative voices as disturbing - Negative voices described as threatening
<p>The role of control in voice-hearing and self-harm</p>	<p>Voices in control of functioning</p> <p>Self-harm as a way of taking back some control from the voices</p> <p>Self-harm and hearing voices maintain each other</p> <p>Voices encouraging self-harm</p>	<ul style="list-style-type: none"> - Voices are described as being powerful - Voices taking away autonomy - Voices disturbing attempts to get help for self-harm - Negative voices associated with stopping the person from enjoying things - Experiencing negative voices as unsettling - Self-harm being a form of control - Self-harming to appease voices - Self-harm as a way of gaining control over the voices - Identifying that lack of task or focus increases likelihood or presence of voices - Self-harm being something personal - Voices instructing one to self-harm - Voices continuing to talk when person is self-harming - Voices encouraging greater injury - Describing an increase in voice severity as a precursor to increased likelihood of self-

		harm
Self-harm in relation to seeking help for voice-hearing	<p>Seeking help from peers and professionals</p> <p>Self-harm being used to seek support for voice-hearing</p>	<ul style="list-style-type: none"> - Seeking peer support for coping with experience - Seeking multiple sources of help - Describing being offered practical support for self-harm more often than emotional support - Help more effective when compassionate and non-judgemental - Extreme self-harm acting as a way of seeking help for hearing voices - Self-harm acting as a 'gateway' to get required help for hearing voices

Appendix L – Example of a memo

This memo was an initial attempt to categorise the focused codes pertaining to stigma, prejudice and discrimination. The memo illustrates that initially the codes felt disconnected. Later on in the analytic process it was clear that these codes could all be categorised together under ‘Self-harm as a way of managing the prejudice associated with voice-hearing’.

“Participants have identified feeling prejudiced against for voice-hearing AND self-harm although it seems like the prejudice associated with voice-hearing is worse for most. There are also codes referring to labels associated with hearing voices including being ‘dangerous’ and how these should be challenged because they cause distress. Negative judgement from others seems to be understood by participants as others not understanding voice-hearing and therefore judging it. Self-harm seems to be a way of coping with this. Currently unclear how well these ideas fit together.” (Research memo, 2nd March, 2017).

Appendix M – Quantitative guidelines

Checklist

Study identification: (Include full citation details)		
Study design: Refer to the glossary of study designs (appendix D) and the algorithm for classifying experimental and observational study designs (appendix E) to best describe the paper's underpinning study design		
Guidance topic:		
Assessed by:		
Section 1: Population		
1.1 Is the source population or source area well described? Was the country (e.g. developed or non-developed, type of healthcare system), setting (primary schools, community centres etc.), location (urban, rural), population demographics etc. adequately described?	++ + – NR NA	Comments:
1.2 Is the eligible population or area representative of the source population or area? Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)? Was the eligible population representative of the source? Were important groups under-represented?	++ + – NR NA	Comments:
1.3 Do the selected participants or areas represent the eligible population	++	Comments:

<p>or area?</p> <p>Was the method of selection of participants from the eligible population well described?</p> <p>What % of selected individuals or clusters agreed to participate? Were there any sources of bias?</p> <p>Were the inclusion or exclusion criteria explicit and appropriate?</p>	<p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	
<p>Section 2: Method of allocation to intervention (or comparison)</p>		
<p>2.1 Allocation to intervention (or comparison). How was selection bias minimised?</p> <p>Was allocation to exposure and comparison randomised? Was it truly random ++ or pseudo-randomised + (e.g. consecutive admissions)?</p> <p>If not randomised, was significant confounding likely (–) or not (+)?</p> <p>If a cross-over, was order of intervention randomised?</p>	<p>++</p> <p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>2.2 Were interventions (and comparisons) well described and appropriate?</p> <p>Were interventions and comparisons described in sufficient detail (i.e. enough for study to be replicated)?</p> <p>Was comparisons appropriate (e.g. usual practice rather than no intervention)?</p>	<p>++</p> <p>+</p> <p>--</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>2.3 Was the allocation concealed?</p> <p>Could the person(s) determining allocation of participants or clusters to intervention or comparison groups have influenced the allocation?</p> <p>Adequate allocation concealment (++) would include centralised allocation or computerised allocation systems.</p>	<p>++</p> <p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>

<p>2.4 Were participants or investigators blind to exposure and comparison?</p> <p>Were participants and investigators – those delivering or assessing the intervention kept blind to intervention allocation? (Triple or double blinding score ++)</p> <p>If lack of blinding is likely to cause important bias, score –.</p>	<p>++</p> <p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>2.5 Was the exposure to the intervention and comparison adequate?</p> <p>Is reduced exposure to intervention or control related to the intervention (e.g. adverse effects leading to reduced compliance) or fidelity of implementation (e.g. reduced adherence to protocol)?</p> <p>Was lack of exposure sufficient to cause important bias?</p>	<p>++</p> <p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>2.6 Was contamination acceptably low?</p> <p>Did any in the comparison group receive the intervention or vice versa?</p> <p>If so, was it sufficient to cause important bias?</p> <p>If a cross-over trial, was there a sufficient wash-out period between interventions?</p>	<p>++</p> <p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>2.7 Were other interventions similar in both groups?</p> <p>Did either group receive additional interventions or have services provided in a different manner?</p> <p>Were the groups treated equally by researchers or other professionals?</p> <p>Was this sufficient to cause important bias?</p>	<p>++</p> <p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>2.8 Were all participants accounted for at study conclusion?</p> <p>Were those lost-to-follow-up (i.e. dropped or lost pre-, during or post-</p>	<p>++</p> <p>+</p>	<p>Comments:</p>

intervention) acceptably low (i.e. typically <20%)?	–	
Did the proportion dropped differ by group? For example, were drop-outs related to the adverse effects of the intervention?	NR NA	
2.9 Did the setting reflect usual UK practice?	++	Comments:
Did the setting in which the intervention or comparison was delivered differ significantly from usual practice in the UK? For example, did participants receive intervention (or comparison) condition in a hospital rather than a community-based setting?	+ – NR NA	
2.10 Did the intervention or control comparison reflect usual UK practice?	++	Comments:
Did the intervention or comparison differ significantly from usual practice in the UK? For example, did participants receive intervention (or comparison) delivered by specialists rather than GPs? Were participants monitored more closely?	+ – NR NA	
Section 3: Outcomes		
3.1 Were outcome measures reliable?	++	Comments:
Were outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking –)?	+ –	
How reliable were outcome measures (e.g. inter- or intra-rater reliability scores)?	NR	
Was there any indication that measures had been validated (e.g. validated against a gold standard measure or assessed for content validity)?	NA	
3.2 Were all outcome measurements complete?	++	Comments:

<p>Were all or most study participants who met the defined study outcome definitions likely to have been identified?</p>	<p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	
<p>3.3 Were all important outcomes assessed?</p> <p>Were all important benefits and harms assessed?</p> <p>Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison?</p>	<p>++</p> <p>+</p> <p>–</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>3.4 Were outcomes relevant?</p> <p>Where surrogate outcome measures were used, did they measure what they set out to measure? (e.g. a study to assess impact on physical activity assesses gym membership – a potentially objective outcome measure – but is it a reliable predictor of physical activity?)</p>	<p>++</p> <p>+</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>3.5 Were there similar follow-up times in exposure and comparison groups?</p> <p>If groups are followed for different lengths of time, then more events are likely to occur in the group followed-up for longer distorting the comparison.</p> <p>Analyses can be adjusted to allow for differences in length of follow-up (e.g. using person-years).</p>	<p>++</p> <p>+</p> <p>NR</p> <p>NA</p>	<p>Comments:</p>
<p>3.6 Was follow-up time meaningful?</p> <p>Was follow-up long enough to assess long-term benefits or harms?</p> <p>Was it too long, e.g. participants lost to follow-up?</p>	<p>++</p> <p>+</p> <p>–</p> <p>NR</p>	<p>Comments:</p>

	NA	
Section 4: Analyses		
<p>4.1 Were exposure and comparison groups similar at baseline? If not, were these adjusted?</p> <p>Were there any differences between groups in important confounders at baseline?</p> <p>If so, were these adjusted for in the analyses (e.g. multivariate analyses or stratification).</p> <p>Were there likely to be any residual differences of relevance?</p>	<p>++</p> <p>+</p> <p>-</p> <p>NR</p> <p>NA</p>	Comments:
<p>4.2 Was intention to treat (ITT) analysis conducted?</p> <p>Were all participants (including those that dropped out or did not fully complete the intervention course) analysed in the groups (i.e. intervention or comparison) to which they were originally allocated?</p>	<p>++</p> <p>+</p> <p>-</p> <p>NR</p> <p>NA</p>	Comments:
<p>4.3 Was the study sufficiently powered to detect an intervention effect (if one exists)?</p> <p>A power of 0.8 (that is, it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard.</p> <p>Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate?</p>	<p>++</p> <p>+</p> <p>-</p> <p>NR</p> <p>NA</p>	Comments:
<p>4.4 Were the estimates of effect size given or calculable?</p> <p>Were effect estimates (e.g. relative risks, absolute risks) given or possible to calculate?</p>	<p>++</p> <p>+</p> <p>-</p>	Comments:

	NR NA	
<p>4.5 Were the analytical methods appropriate?</p> <p>Were important differences in follow-up time and likely confounders adjusted for?</p> <p>If a cluster design, were analyses of sample size (and power), and effect size performed on clusters (and not individuals)?</p> <p>Were subgroup analyses pre-specified?</p>	++ + - NR NA	Comments:
<p>4.6 Was the precision of intervention effects given or calculable? Were they meaningful?</p> <p>Were confidence intervals or p values for effect estimates given or possible to calculate?</p> <p>Were CI's wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered?</p>	++ + - NR NA	Comments:
Section 5: Summary		
<p>5.1 Are the study results internally valid (i.e. unbiased)?</p> <p>How well did the study minimise sources of bias (i.e. adjusting for potential confounders)?</p> <p>Were there significant flaws in the study design?</p>	++ + -	Comments:
<p>5.2 Are the findings generalisable to the source population (i.e. externally valid)?</p> <p>Are there sufficient details given about the study to determine if the findings are generalisable to the source population? Consider: participants, interventions and comparisons, outcomes, resource and policy implications.</p>	++ + -	Comments:

Appendix N – Abridged research diary

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Appendix O – End of study short report for participants

Dear X,

Research Title: “It’s the way I cope”. How do people who hear voices and also self-harm understand the relationship between the two?

I would like to thank you for taking part in my research study earlier this year. As I’m sure you remember, I asked you questions regarding your experience of voice-hearing and self-harm either recently or in the past. As agreed, I am writing to let you know the results of the study.

This is a summary report and you are, of course, more than welcome to have a copy of the full report once it has met the criteria required for publication (this may be in several months time). I will contact you closer to the time to ask if this is still something you would like.

Why did we carry out this research?

There was very little existing research into links between hearing voices and self-harm. What there was only focused on people who self-harm because a voice has told them to. Of course many people do have this experience and it is important to talk about it but we wondered whether self-harm might function in other ways for people as well as this. We also thought it was important to directly ask people to talk about their experiences to make sure the results represented real experience.

Results

Altogether I interviewed 12 adults. From the interviews, one main theme was found and four smaller themes.

The main findings were:

- Participants mainly spoke about how self-harm was linked to their experience of hearing negative voices.
- Participants felt that self-harm could sometimes be a way of coping with negative voices.
- Some participants said that they had experienced prejudice or discrimination from other people because they heard voices. These

people included members of the public, people they knew and also healthcare professionals. Some participants spoke about how self-harm helped them to cope with their voices so they did not have to tell other people about them. This then helped them to avoid the prejudice of other people.

- Some participants said self-harm and hearing voices were linked by the idea of control. A few participants spoke about how their negative voices told them to self-harm so they did so to make them shut up. Other participants said self-harming helped them to take back a little bit of control from the voices because the participant was making the choice to self-harm
- Lastly, some participants spoke about how self-harm has been a way of getting help from other people for their experience of hearing voices. Some people said, for example, that others only realised they needed help when they found out they had been self-harming.

What can be learnt from this?

After looking at the results of the research, some suggestions were made for how clinicians might better help people and what we might need to do some more research on in the future.

Suggestions for clinicians:

- Clinicians should treat service-users as individuals and take time to ask about what features of their voices cause most distress. It might then be easier to look at alternative coping mechanisms.
- Clinicians should recognise that people may find it difficult to or may not want to stop self-harming straight away. They should remember that sometimes self-harm is a way of preventing further damage.
- Mental health services should promote peer support services where people from different mental health teams can meet and discuss their difficulties if they want to.
- Appropriate training for staff about voice-hearing and self-harm should be delivered by service-users to help reduce prejudice and poor treatment by staff.

- Clinicians should challenge stigma and prejudice when they see it happening (in person or in the media).

Suggestions for future research:

- Research that asks people about the links between self-harm and seeing/feeling things others cannot.
- Research that asks clinicians about how they understand the link between voice-hearing and self-harm. It would be interesting to see if this is the same as the way participants have described it in this study.

If you have any further questions about this you can email me using the research email address (hearingvoicesselfharmresearch@gmail.com) or ask a member of the nursing team to ask me to come and speak to you (inpatients only).

I would like to thank you again for taking the time to participate in this research. Your decision to take part was greatly valued.

Best wishes,

Holly Tett

Trainee Clinical Psychologist,

Salomons Centre for Applied Psychology

2017

**Appendix P – End of study declaration for NHS Ethics REC panel, HRA panel
and R&D panel**

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**Appendix Q – Summary of results form for NHS REC panel, HRA panel
and R&D panel**

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Appendix R – Author guideline notes for publication

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