How do young people accessing mental health services describe and understand emotional distress?

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If we knew what it was we were doing, it would not be called research would it?
Albert Einstein

Abstract

Background and aim: There has been growing acknowledgement of the role of emotional distress in the development of mental health difficulties yet despite adolescence being a complex developmental stage, where individuals develop an increasingly sophisticated conceptual framework for their emotional experiences, research has focused on normative adult populations. Furthermore, a lack of shared concept and pragmatic research considerations has led to a diverse conceptualisation of emotional distress and the use of quantitative methodology. Very little qualitative research has been conducted examining the subjective experiences of young people experiencing mental health difficulties so the aim of this study was to explore how young people accessing mental health services talk about and understand their experience of emotional distress.

Method: Eight interviews were conducted with young people aged between 14 and 17 years old who were accessing a Tier 4 Child and Adolescent Mental Health Service (CAMHS). The interview transcripts were analysed using thematic analysis.

Results: Four themes were produced in the analysis and were 1) Experience of emotional distress: Emotions are uncontrollable, 2) Impact of emotional expression: Isolations, 3) Management of emotional distress: Self regulation and 4) Reaction to emotional distress: Service provision. They highlight the young people's understanding of emotional distress and the associated consequences including response by professionals, difficulties with interpersonal relationships and the use of coping mechanisms.

Discussion: The young people described and understood their experiences of emotional distress to have had significant and ongoing impact on their lives. These findings provide support for existing literature but also make new contributions to the evidence base by representing the voice of a marginalised and difficult to access service user group. The theoretical implications of the results consider the importance of continued qualitative investigation in how young people understand and experience emotional distress. Clinical implications were discussed in terms of the commonalities in the conceptualisation of distress between young people and clinical practice. Future directions for research were also discussed.

Contents

Chapter 1 – Introduction

Chapter 2 – Methodology

Chapter 3 - Analysis

Chapter 4 - Discussion

Tables

Figures

<u>Chapter 1 – Introduction</u>

1.0 Introduction

Adolescence is a complex developmental stage where individuals develop an increasingly sophisticated conceptual framework for their own emotional experiences. It is surprising therefore, that little research has focused on the subjective descriptions and experiences of emotional distress within this group with clinical populations of young people largely ignored (Scott-Brown & Wright, 2003).

Throughout this thesis it is proposed that emotional experiences are bound in the context in which they occur encompassing environmental, internal, developmental, interpersonal and cultural factors (Ehrenrich, Fairholme, Buzella, Ellard, & Barlow, 2007; Zeman, Klimes-Dougan, Cassano, & Adrian, 2007). It has been argued, however, that current day diagnostic medicine ignores the individual explanation, language and societal influence in both the experience and treatment of distress (Parker, Georgaca, Harper , McLaughlin, & Stowell-Smith, 1995). Without the knowledge of personal experience within this medical framework, where assessment and evaluation is intimately tied to clinical diagnosis (Strosahl & Robinson, 2004), mental health services and clinical teams will struggle to assess the efficacy and process of treatment models within the NHS. Hill (2006) has championed for the voice of young people to be accessed and promoted to strengthen the existing evidence base in line with current health service policy to develop more client centred care (Department of Health, 2015). Indeed, the lack of involvement of young people in service planning has been highlighted as needing consideration in the commissioning of tier 4 services (McDougall, Worall-Davies, Hewson, Richardson, & Cotgrove, 2008).

<u>1.1 Overview of the chapter</u>

Due to the multifaceted nature of emotional distress this chapter will first delineate the construct of emotion and how it will be positioned in the context of this research as both a holistic and functional concept. A definition of emotional distress will be provided and then there will be an examination of the paradigm of emotional distress and how it is conceptualised, defined and measured. Due to the limited amount of research conducted in clinical adolescent populations this section will also use the adult mental health as an analogue evidence base.

The limitations of this evidence base and the methodologies used will then be considered.

Following this will be a discussion regarding the importance and uniqueness of the adolescent developmental period and how this may impact on the emotional distress of the individual. A brief discussion of clinical intervention for emotional distress will follow this and finally, the chapter will be concluded by drawing together the main conclusions from the literature and will outline the rationale for this research.

1.2 The construct of emotion

Zeman et al. (2007) have highlighted how the lack of shared agreement and understanding of the construct of emotion contributes to the difficulty of conducting empirical work in this area. They suggest it is critical for researchers to clearly state their definitions of emotions to encourage helpful dissemination and communication between researchers from a variety of ontological and epistemological positions. Indeed, As Ehrenreich et al, (2007) comment,

'the marriage of emotion topics and clinical ones is not necessarily easy, from either a conceptual or practical perspective...issues of variability and accessibility across context and development may make such constructs difficult to measure or apply with accuracy or consistency in clinical settings' (p. 1).

For clarification, therefore, this research considers emotion as a holistic concept and subscribes to the multi modal model of emotions proposed by Solomon (2002). Here, emotions are described as a complex bodily phenomenon that involve behaviour, physiology and cognitions that occur within a social context. Emotions are, therefore, positioned as attempts by the individual to establish, maintain, interrupt or end the relationship between themselves and their internal or external environment (Zeman et al., 2007). To understand this, Lambie and Marcel (2002) propose a two part process. One part considers the individual's awareness of the emotion as a conscious experience, essentially *"how we feel, why we feel the way we feel and what can we do about it"* (Stegge & Terwogt, 2007, p.271). The second part is phenomenological in nature considering what the emotion *is like* and what we do to manage them.

To expand this discussion further to incorporate the social context, it has been proposed that certain emotional responses transcend culture and are universal to human beings worldwide; fear, anger, sadness, happiness, surprise, disgust and contempt (Ekman & Friesen, 1986). These facilitate our interpersonal communications and relationships, memory and motivational states and are elaborated and adapted throughout experiences across the lifespan (Kemper, 1987) leading to the development of more complex emotional states. As these develop, so do the terms for expressing emotions which name not only individual experience but also provide the foundation for expectations in interpersonal behaviour and socially constructed situations (Kirmayer, 1989). Indeed, emotions are conceptualised to be essential to our integration and survival within society (Mennin & Farach, 2007).

1.3 Emotional distress

Emotional distress is defined, therefore, in this study as an individual's experience of negative or unwanted emotions or emotional states that are sufficiently intense to disrupt or interfere with their day to day lives and interpersonal relationships.

1.3.1 Clinical considerations: The medicalisation of distress

There has been an increasing medicalisation of emotional distress (Conrad, 2007) in both clinical practice and research. As a term, it has become synonymous with functional psychiatric diagnoses and utilised within a medical framework and the application of a disease model to an individual's thoughts, feelings and behaviours (Division of Clinical Psychology (DCP), 2013). Yet it remains a nebulous and often an assumed concept where definitions are not provided and has led to the interchangeable use of terms 'emotional distress', 'psychological distress', 'mental illness', 'psychopathology' and 'mental distress'.

However, there has been recent agreement where it is positioned that, within clinical work and research, an individual who is unable to manage their emotional responses to day to day life events and everyday situation will experience longer and more severe periods of distress that evolve into diagnosable forms of mental illness (Aldao, Nolen-Hoeksema, & Schweiser, 2010; Mennin, Holoway, Fresco, Moore, & Heimberg, 2007; Nolen-Hoeksema, Wisco, & Lyobomirsky, 2008). So within this challenging area let us consider

how emotional distress in mental health is examined, measured and treated with an examination of the idea of emotional management within clinical research first, then within clinical intervention and work. The evidence base of studies investigating emotional distress in clinical adolescent populations is sparse, the evidence base from adult mental health samples will be surmised to provide a parallel evidence base within which to frame the proposed research.

1.3.2 Research considerations: The formulation of emotional distress in the literature situated in clinical samples.

Emotions are proposed to serve a functional purpose for an individual to navigate life (Gross, 2002; Kirmayer, 1989; Mennin & Farach, 2007) and within clinical research there has been a growing acknowledgement and interest in the role of emotional distress in the development of mental health difficulties (Gross, 2007; Rottenberg & Johnson, 2007). It has become increasing clear disturbances in emotion are associated with many different psychological difficulties (Aldao et al., 2010; Cole & Deater-Deckard, 2009; Cole, Michel, & Teti, 1994; Daughters, Gorka, Rutherford, & Mayes, 2014; Gross & Munoz, 1995; Mullin & Hinshaw, 2007; Sheeber, Hops, Alpert, Davis, & Andrews, 2009; Sloan & Kring, 2007 Southam-Gerow & Kendall, 2002; Tyler & Melander, 2010) and work has focused on demonstrating that disorder or dysfunction in emotion is what delineates those who are experiencing mental health difficulties including depression, anxiety, psychopathy and schizophrenia (see Kring & Bachorowski, 1999).

Given that emotional distress is a key diagnostic criteria within the vast majority of mental health diagnosis (American Psychiatric Association (DSM 5), 2015; Kring & Werner, 2004) it is perhaps surprising that rather than considering the nature of emotional distress, the current evidence base within clinical populations does not specifically consider the construct of 'emotional distress'. Rather it explores one particular facet of distress and that is how individuals respond to and try to manage their distress. This is conceptualized and examined in the form of emotion regulation and dysregulation (Mennin & Farach, 2007).

1.3.2.1 Model of emotion regulation and dysregulation

It is proposed that the elicitation, expression, and regulation of emotion are interdependent components of emotion that interact through all phases of the emotional experience from its generation to termination (Campos, Frankel, & Camras, 2004; Feng et al., 2009). Emotion regulation is associated with mental well being and is described as processes where an individual experiences their emotions in a flexible way and as such, is aware of and modifies the impact of their emotions on their behaviour and subsequent interpersonal interactions (Gratz & Roemer, 2004; Zimmerman, 1999).

Difficulties in these regulation strategies are associated with emotional distress within a number of mental health diagnoses including anxiety (Mennin et al., 2007), eating disorders (Bydlowski et al., 2006), depression (Rottenbery, Gross, & Gotlib, 2005) and borderline personality disorder (Lynch, Trost, Salsman, & Linehan, 2007). In fact, maladaptive strategies rather than the absence of emotion regulation strategies have been hypothesised to have the more significant impact on emotional distress (Aldao et al., 2010). Emotional distress is, therefore, considered as a product of dysfunctional emotional processes (Gross & Munoz, 1995; Mennin, Holoway, Fresco, Moore, & Heimberg, 2007) and in this literature, these process are considered as 'emotion dysregulation'

Dysregulation of emotion within the context of resulting emotional distress in psychopathology is argued to have two forms (Berenbaum, Raghaven, Le, Vernon, & Gomez, 2003; Cichetti, Ackerman, & Izard, 1995; Mennin et al., 2007). The first is where the regulation strategy used is unsuccessful in reducing the distress and the second is where the short term benefits of using a particular regulation strategy are outweighed by the longer term cost of actual increased distress (Campbell-Sills & Barlow, 2007).

In relation to emotional distress, it is important to consider this literature as it demonstrates important factors in how emotional distress is currently described and understood. Namely that, whilst it is integral to the diagnosis of mental health difficulties (REF), emotional distress is conceptualized as an end product of poor emotion regulation and measured in terms of level of clinical symptoms. Within the psychological model of stress and coping, emotion regulation strategies are formulated to be employed in the hoped avoidance or reduction

in emotional distress (Aldao, Nolen-Hoeksema, & Schweixer, 2010) yet we know very little about the invidual's understanding or experience of this distress Let us examine this in the adult literature first.

1.3.3 The evidence from adult clinical samples

Within adult mental health research, 'emotional distress' as a concept has not been specifically researched. Rather, distress had been measured, through mainly quantitative methods, as reported levels of symptomatology through the use of self report questionnaires with the focus of work examining how individuals respond to this distress, often operationalised as predetermined emotion regulation strategies. For example, the Emotion Reguation Questionnaire (ERQ: Gross & John, 2003) asks individuals to rate on a 7 point likert scale how much they strongly disagree or agree with 10 statements such as 'When I want to feel less negative emotion, I change what I am thinking about. Questionnaires such as this have been utilized to compare and contrast groups with and without psychiatric diagnoses in efforts to understand how distress is understood (i.e. controllable vs uncontrollable) and responded to differently e.g. the Cognitive Emotion Regulation Questionnaire (CERQ: Garnefski & Kraaj, 2003). In other efforts to gain an understanding of emotional distress, questionnaires are often utilized in this research group that assess clinical level of symptomatology for a specific clinical difficulty at particular time points such the GAD-7 for anxiety or PHQ-9 for depression.

Whilst these types of measurement are helpful in providing levels of distress and the strategies used by those experiencing mental health difficulties to manage their distress, they cannot provide a richer understanding of emotional distress. By their very nature, with predetermined answers and single scores, these measures are unable to explore how individuals describe and understand emotional distress leaving researchers unable to make potential links between these scores and strategies to how an individual relates to their experiences of distress.

Despite these limitations, important findings have been made in investigating emotional distress in adult clinical populations. Current literature proposes that when adults with mental health difficulties have negative beliefs about the acceptability of a particular emotion, they are more likely to have a lower perceived ability to cope with emotional distress (Campbell-Sills, Barlow, Brown,

& Hoffman, 2006). For example, when adults experiencing mental health difficulties report feeling overwhelmed by negative emotions, studies have found them more likely to use cognitive strategies to minimise or avoid this distress such as denial and suppression (Garnefski et al., 2002). Suppression of emotional expression, that is the intentional reduction of their outward expression of emotion and subjective experience by an individual has been found as helpful in the short term but less effective in reducing emotional distress in the longer term (Gross, 2002; Gross & Thompson, 2007). In fact, in trying to avoid their emotional distress, individuals experience increased physiological arousal and, paradoxically, less ability to actually suppress these cognitions (Wegner, Schneider, Carter, & White, 1987; Trinder & Salkovskis, 1994). This is commonly found in adults diagnosed with anxiety (Aldao et al., 2010; Wenzlaff & Wegner, 2000), eating disorders (Aldao et al., 2010) and obsessive compulsive disorder (Tolin, Abramowitz, Przeworski, & Foa, 2002).

There is also an associated increase in self harm with suppression of emotional distress (Najmi, Wegner, & Nock, 2007) and the finding that those experiencing clinical levels of distress have a higher threat perception and are more like to catastophize in the face of difficult life events (Aldao et al., 2010; Folkman & Lazurus, 1986).

It can be argued here that adults experiencing clinical levels of emotional distress understand it to be something that needs to be controlled, avoided or suppressed and research concentrates in its measurement rather than description. However, what this literature does not examine is the nature of their distress and what it means for adults experiencing emotional distress in the context of their mental health difficulties and why.

In a similar vein, problem solving skills, formulated within the literature as a conscious attempt by an individual to change a stressful situation or emotion and contain its consequences, have been shown to be poor in individuals experiencing clinical levels of distress e.g. depression (Aldao et al., 2010; MIllings & Moos, 1982) anxiety (Aldao et al., 2010; Chang, Downey & Salata, 2004) and eating disorders (VanBoven & Espelage, 2006). Whilst this suggests that distress is associated with poor problem solving and the development and maintenance of these disorders, it does not help us understand how the individual constructs their experience of distress and how this affects their ability

to problem solve. It is important to consider how an individual's description and experience of distress interact with these beliefs.

Avoidance (experiential, behavioural and psychological) is presented as risk factors in the development of and continuation of emotional distress and maladaptive behaviour in adults experiencing mental health difficulties. Experiential avoidance, defined as the suppression or avoidance of any psychological experience including emotions has been linked to increased emotional distress (Wenzlaff & Wegner, 2000) and found to be used as a coping mechanism in those adults experiencing clinical levels of depression, anxiety and eating disorders (Aldao et al., 2010). Behavioural avoidance appears to be considered in a similar way with situational avoidance and social withdrawal positioned as efforts made by an individual to reduce their levels of emotional distress. This short term strategy of active avoidance has, however, been associated with long term increased levels of emotional distress (Campbell-Sills & Barlow, 2007).

In the current adult mental health literature emotional distress has not been labeled as such, rather distress has been studied under the guise of emotional regulation whereby the strategies used by an individual to manage their distress are the focal point of investigation. Moreover, distress is assessed in relation to reported increase or decrease in symptomatology through self report quantitative methods. However, in line with the current proposition that disturbances in emotions are associated with mental health difficulties (Aldao et al., 2010; Tyler & Melander, 2010) there is evidence to suggest that adults with mental health difficulties understand and experience emotional distress as overwhelming and an experience that needs to be controlled, miminised or avoided. Whilst important to consider the strategies utilised when distress, this current literature leaves gaps in our understanding of how adults with mental health difficulties conceive of their experiences of emotional distress.

However, a recent study by Martorell-Poveda, Martinez-Hernaez, Carceller-Maicas and Cornea-Urquiza (2015) attempted to address this lack of subjective knowledge by conducting the only qualitative study to date examining emotional distress in an adult clinical population. They noted the need to include first hand personal experiences and lay knowledge of those experiencing mental health difficulties and focused their investigation of the strategies young people (aged

between 17 and 21) used to cope with their situations of emotional distress. The authors conducted in-depth face to face interviews with young people from three groups, those with diagnosed depression, those with self perceived emotional distress and a control group and used the principles of hermeneutic theory and the ethnographic method to analyse the data.

In terms of how young people experience emotional distress, Martorell-Poveda et al. (2015) frame their study within a coping model and hypothesise that it is experienced by the individual as their own responsibility and that they feel they should be able to resolve it through their own resources. From this, the authors grouped the self care strategies of the young people into four areas; 1) resources that reinforced the individuality of the young person, 2) support from their adult world, 3) the channeling of stress, caused by emotional distress, through physical activity and 4) artistic and sensory expression.

Of particular relevance to how emotional distress is understood was how young people spoke about mobilising their own personal resources to cope with their distress believing this self reliance was essential if and when their distress increased. When they felt they did not have the coping resources necessary, at this point young people expressed their distress in the context of peer relationships. Despite this often being reported as the space from where the distress originated, Martorell- Poveda et al. (2015) found that within the narratives of the young people was their consideration that there 'is always mutual support in friendships' and these relationships restored confidence in their abilities to manage distress.

The participants also spoke about how trust was necessary within interpersonal relationships to be able to express their emotional distress and 'get the problem out'. Within this context, they reported being able to talk to a trusted friend or family member and express their distress through emotions, feelings, concerns and wishes, something conceptualised by the authors as 'externalisation' (Martorell_Poveda et al., 2015).

This piece of qualitative research is a valuable addition to the current evidence base that examines emotional distress. Not only does it provide a subjective perspective in how young people understand emotional distress but it highlights the need of young people, when experiencing distress, to have a 'dialogic and

intersubjective encounter with the other' (p. 10, Martorell-Poveda et al., 2015) to restore their well being. The narratives of the young people suggested that active listening from the other, without judgement and perceived threat to self esteem and autonomy, served to value their subjective experiences as an individual rather than as a distressed being or diagnostic category. This fostered a sense of autonomy and self efficacy within the individual. This description of how young people understand emotional distress and the mechanisms they use to cope with it is of crucial relevance to any interpersonal relationships and therapeutic alliances within the life of an individual experiencing emotional distress.

Whilst the study above has elaborated on the experience of emotional distress in young adults, there still remains a gap within the literature which is our understanding of how *adolescents* describe and understand emotional distress. It has already been noted that there is a lack of empirical research conducted with clinical adolescent populations in comparison to adults (Scott-Brown, & Wright, 2003) which is curious considering that mental health difficulties in adulthood often stem from difficulties observable in childhood and adolescence (Daughters et al., 2014; Kim-Cohen et al., 2003; O'Connor, 2011, Zahn-Waxler, Klimes-Dougan, & Slattery, 2000). Indeed, it is important to consider how emotional distress is conceptualised, measured and defined within clinical adolescent populations. In this way we can perhaps note any differences between adults and adolescents experiencing clinically significant level of distress but also begin to develop an understanding of the pervasive nature of emotional distress within this population (Daughter et al., 2014).

1.3.4 The evidence from adolescent clinical samples

As the literature examining this group is limited, yet particularly relevant to the research question, a careful search of five databases was conducted covering the period from 1937 to 2015 (week 2)); including PsychINFO®, PsychARTICLES®, CINAHLplus (nursing and allied health), Child Development and Adolescent studies, Academic Search complete (multidisciplinary). The keywords used within the search were 1) "adoles$" or "young people" or "young person$" or "teenage" or "youth" 2) "affect" or "emotion$" or "distress" or "regulation" or "alexithym$" and 3) "psychopathology" or "mental health" or "mental ill$". This yielded 834 papers and the following inclusion and exclusion

criteria were applied. Inclusion criteria were: adolescent samples, clinical population and mental health difficulties. Exclusion criteria were: non mental health populations, populations with learning disabilities, samples of children (up to 12 years of age), adults (from 18 years on), population samples, theoretical papers without a sample, papers without an English translation available and studies not published in peer reviewed publications. This led to 183 papers deemed suitable for inclusion. However, after further examination of abstracts using the inclusion and exclusion criteria, this sample was reduced to 67 papers.

Similarly to the adult clinical populations, the examination of distress within this population is examined under the guise of how young people respond to their emotional distress. Gross (2007) argues that rather than being passive recipients of their own emotions, in efforts to manage their experiences of distress, it has been proposed that adolescent's begin learning how to exert control over the emotions they experience (Gross, 1998) and research has suggested that it is the inability to manage difficult emotions, due to less effective ways of coping, that differentiates distressed and non distressed peers (Feng et al., 2009). Therefore, clinical levels of emotional distress are proposed to be as a result of a young person not being able to regulate their emotions when distressed.

Within this literature, emotional distress is assessed by levels of reported symptoms and diagnostic criteria with self report questionnaires offering predetermined strategies for the young people to rate in relation to their responses to distress. The regulation questionnaires are from the same group used by those in adult clinical samples[1] but levels of symptomatology are often measured using age appropriate self report measures such as the strength and difficulties questionnaire as one example (SDQ: Goodmans, 1997)

However, whilst still framed within a stress and coping model, in contrast to the clinical adult literature, emotional distress is currently conceptualised as both a product of but also a cause of dysregulated emotion within adolescent populations experiencing mental health difficulties. This body of work also offers

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[1] The limitations of this will be explored in section ?.??

insights into how adolescents have difficulties in describing and understanding emotions and subsequent distress.

1.3.4.1 Emotional distress and behaviour

Within clinical adolescent populations emotional distress has been formulated as a cause of dysfunctional behaviour which is proposed to have two functions. One is that it is a young person's attempt to regulate their distress by either relieving or altering their negative emotional states and the other is it is a form of communication to let others know how they are feeling. These dysfunctional behaviours are conceptualised as self harm and suicide attempts. In addition to this, some work has been carried out examining the social interactions of adolescents experiencing mental health difficulties.

Self harm is proposed to be a functional mechanism to release tension and depression (Nixon, Cloutier & Aggarwal, 2002; Ohmman et al. 2008), alter negative emotional states (Sim et al. 2009) and work as a form of emotional expression (Suyemoto & Macdonald., 1995)[2]. Nock and Prinstein (2005) examined antecedent contextual influences on self harm. In their sample (n=108) of adolescents consecutively admitted to hospital, negative automatic reinforcement factor was the most frequently endorsed reason for self harm, functioning as a mechanism to avoid their internal emotional states. In terms of emotional distress, these findings could perhaps suggest that young people experiencing mental health difficulties understand emotional distress as overwhelming and to be reduced or minimised and something only they can influence

High levels of emotional distress, expressed through more frequent and multiple types of self harm, have been proposed to differentiate between suicide ideas and attempts (Zlotnick, Donaldson, Spirit, & Pearlstein, 1997). Similarly, Esposito, Spirito, Boergers and Donaldson (2003) find more frequent major self mutilation, anger and affect dysregulation in adolescents with multiple suicide attempts compared to those with a single attempt. Of note, compared to their adult counterparts, adolescent suicide attempters have been found to have

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[2] Of note, throughout the literature self harm has been used as an umbrella term to cover self injurious behaviour, non suicidal self injury or self mutilative behaviour (SMB).

significantly more frequent self injury, number of self injury types and more expressed anger (Zlotnick, Wolfsdorf, Johnson & Spirito, 2003). In terms of the current literature, self harm and suicide attempts are presumed to be indicative of high levels of emotional distress and coping mechanisms made by young people in response to being overwhelmed by their distress. What remains unknown, however, is how young people experiencing such extreme levels of distress describe and understand it. This research paints a largely behavioral picture in adolescent emotional distress and would benefit from an examination of the internal and subjective description and understanding of distress.

In keeping with the proposal that emotional distress is expressed in behavioural form other clinical difficulties have been examined. In a bipolar disorder sample of adolescents, Goldstein, Miklowitz, & Mullen (2006) found that despite this clinical group having the same reported social knowledge as healthy controls, the authors found that they exhibited significantly higher levels of inappropriate assertive or impulsive behaviours. Furthermore, Adrian et al, (2009) found that behavioural difficulties and poor impulse control in response to experiencing negative emotions differentiated their sample of adolescents consecutively admitted to a psychiatry unit over 12 months. In relation to this, exclusion from peer group was also associated with distress (Adrian et al., 2009).

Self harm and suicide have also been associated with difficulties in social contexts. When facing interpersonal difficulties, suicidal adolescents have been found to employ social withdrawal as a behavioural strategy in the face of interpersonal difficulties and their experiences of distress (Spirito, Overholser and Stark., 1989). Invalidating family environments have been directly linked to deliberate self harm in females, where self harm was described as a behavioural function to alleviate distress (Sim et al., 2009). This relationship was also partially mediated by an individuals lack of awareness and expression of emotions.

In terms of our understanding of emotional distress, these behaviours described as dysfunctional or maladaptive could be construed as functional by the individuals and representative of their efforts to reduce their experience of distress. Furthermore, there behaviours can have consequences for social

relationships which may or may not exacerbate levels of distress. It is therefore important to gain a more qualitative understanding of the young person's description and understanding of their distress to explore how and why these behaviours fit into their internal model of distress.

1.3.4.2 Emotional distress and cognitions

In this literature, cognitive errors have been found in young people experieincing clinical levels of distress and associated with increased levels of self harm (Weismore & Esposito-Smythers, 2010). Errors have included overgeneralization, catastrophizing, personalizing and selective abstraction. In a study that compared clinical and control groups, Orbach et al., (2007) investigated the susceptibility to threat appraisal of three groups of adolescents; a non clinical control group, a group of suicidal in patients and a group of non suicidal inpatients. The authors found the two clinical groups perceived a problem solving task as more threatening than the control group. The hyper sensitivity to threat, in addition to higher hopelessness scores and a limited ability to generate solutions for the task were simultaneous predictors of suicidality. Similarly, Carthy, Horesh, Apter and Gross (2010) found clinically anxious children (mean age 13.42 years) experienced higher levels of threat appraisal than non anxious children (mean age 13.74 years).

Cognitive distortions have been linked to a negative view of self within clinical adolescent populations (Weismore & Esposito-Smythers, 2010) yet the mechanisms of how these are linked have not been fully examined. This suggests that our understanding of emotional distress is not yet comprehensive. Finding out more about how young people describe and understand their emotional distress could perhaps provide some insights into the association between cognitions and emotional distress.

1.3.4.3 Difficulties in labeling, understanding and expressing emotion.

Difficulties in labelling, accepting and expressing emotions are proposed to inhibit an individual's understanding of their emotional distress therefore making this an important area to consider. These difficulties have been observed in adolescents across a range of mental health difficulties.

O'Kearney and Dadds (2005) noted emotional language deficits, less use of emotional terms and difficulties explaining them, in a clinical population of adolescents with internalising and externalising disorders. Lambert & de Man (2007) found female adolescents who engaged in self mutilation experienced particular difficulties in identifying their emotions and differentiating them from their physiological states. Moreover, van Rijn et al. (2011) investigated the affective dysfunction of adolescents at risk for psychosis and found that in comparison to controls, this group demonstrated difficulties in identifying and verbalizing their emotional states. The authors also found that this was subsequently associated with impairments in social functioning.

Zonnevylle-Bender, Van Goozen, Cohen-Kettenis, van Elberg and van Engeland (2002; 2004) conducted two studies in 2002 and 2004 with female adolescents with eating disorders in attempts to assess the ability of the individual to consider their emotional states when experiencing a mental health difficulty. The first study in 2002 reported the anorexic group scored higher on being unable to access their emotional state and significantly worse in labelling emotions than the control group, particularly when asked to free associate. In their second study, Zonnevylle- Bender and colleagues (2004) compared two female clinical groups with anorexia or internalizing difficulties to age matched controls and found slower processing and labelling of emotions within both the clinical groups. Furthermore, Zonnevylle-Bender et al. (2005) found that an adolescent eating disordered population demonstrated significant discrepancies between their reported emotional state and what their physiological state indicated where the participants reported more feelings of tension and depression than their physiological responses signified. There are two possible explanations for this, either the individual is reporting what they perceive to be the expected response from them or they have difficulty assigning an emotional label to the physical feelings they are experiencing, suggestive of inherent emotion labelling difficulties. For either of these hypotheses, the concealment of emotional states to either self or other is a key area for further research as repression of emotions have also been found in suicidal in patients (Apter et al, 1997) and can therefore be formulated to play a significant role in poor adaptation in adolescents with clinical difficulties.

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Understanding emotions is a prerequisite for an individual to be able to navigate their day to day life and interpersonal experiences (Menin & Farach, 2007). Therefore, it is of key importance to deconstruct these difficulties in emotional understanding experienced by young people with mental health difficulties. If we can find out more from the perspective of young people about how they describe distress, the difficulties they might face in labelling, understanding and ultimately expressing it, we might begin to understand how emotional language plays such a crucial role in distress.

To conclude this section on distress examined in adolescent populations, whilst there are no qualitative studies examining emotional distress in clinical adolescent populations, there is a quantitative evidence base of work exploring how young people respond to and try to manage their distress. Behavioural attempts to reduce distress have been labelled as dysfunctional or maladaptive but are understood by the young people to be a functional mechanism for alleviating distress. Cognitive errors and distortions have also been associated with emotional distress but little is known as to whether they are the cause of or consequence of distress. Finally, difficulties in understanding, labelling and expressing emotions have been found in those experiencing clinically significant levels of distress. All of these findings are useful building blocks in understanding the variety of ways in which emotional distress impacts on an individual. What is missing, however, is that individual's perspective as to their own understanding of their distress, the nature of it and what that means for associated coping strategies highlighted here.

Before we move on, however, there should be consideration of methodological issues that translate across both the adult and adolescent literature and should be held in mind when considering why it is important to study emotional distress for the subjective perspective of the individual experiencing it.

1.3.5 Critique of the adult and adolescence evidence base

1.3.5.1 Lack of unified construct

A lack of a unified definition of emotional distress is evident within this review. This lack of clarity and focus is not perhaps surprising given the complex nature

of subject (Zeman, Cassano, Perry-Parish, & Stegall, 2007) but this non definition means assumptions are made about the universality of language, specifically that all researchers and research participants have a shared understanding about distress and what is being measured and defined in research.

In addition to this, within this review, emotional distress was often conceptualised as symptomatology where more symptoms were assumed to indicate more distress. Fonagy et al. (2002) highlight the need for outcome and research measures to cover more domains than just symptoms due to the mulititude of domain within which an individual exisits on a day to day basis including interpersonal and familial domains. Indeed, current quantitative methods assess level of distress rather than gain a description of it. A qualitative exploration into the construct of emotional distress would hope facilitate this broader approach.

1.3.5.2 Quantitative methods and use of self report measures

The vast wealth of studies within mental health samples have predominantly examined levels of emotional distress and emotion regulation strategies using quantitative methodology within the context of psychiatric diagnoses (Aldao et., 2010). This has led to a proliferation in the development and use of self report measures. For example, in a meta analytic review of emotion regulation across psychopathology, Aldao et al. (2010) found approximately 70 different questionnaires, checklists or scales used to measure emotion regulation in 114 papers[3]. This confounds the applicability of research findings and makes the understadning of emotional distress and even more difficult task. So many measures suggests that there are mutiple descriptions and interpretations within the research community about what emotional distress is and how it is best defined and measured. This is notwithstanding the multiple interpretations of the participants themselves.

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[3] For example, AAQ: Acceptance and Action Questionnaire; ADIS for DSM-IV: Anxiety Disorders Interview Schedule for DSM-IV; AEI: Anger Expression Inventory; AES: Anger Expression Scale; ASI: Anxiety Sensitivity Index; BAI: Beck Anxiety Inventory; BARQ: Behavioral Anger Response Questionnaire; BDI: Beck Depression Inventory; BES: Binge Eating Scale; BITE: Bulimic Investigatory Test Edinburgh; BSQ: Body Sensations Questionnaire; BULIT: Bulimia Test.

Almost all the studies use self report questionnaires, relying on predetermined descriptions of what strategies individuals might use when feeling distressed, in addition to an assumption of what constitutes emotional distress. For example, in the development of their Emotion Regulation Questionnaire (ERQ), Gross and John (2003) proposed that individuals exert control over their emotions using a range of strategies to influence what emotions an individual has and when. The authors designed a likert scale self response questionnaire to assess how an individual utilises cognitive reappraisal and expressive suppression when trying to control their emotions. There are 10 statements that speak to positive and negative emotions yet no clarification of what these emotions might be and whether these strategies are used at times of distress is given. Whilst it may provide very useful information of what a person does when trying to control their emotions, it does not provide any insight into how their understanding an experience of their distress might affect their use of such strategies.

In addition, to be able to accurately rate emotional experience, and complete a self report measure, there is a presumption that the individual can understand and recognise the emotions they are being asked about as well as being able to recall and accurately describe this information (Aldao et al., 2010; Lewis et al., 2010; Messer & Fremouw, 2008). The extent to which participants can accurately self report on their emotions and emotions regulation strategies is disputed (Aldao et al., 2010; Robinson & Clore, 2002) with evidence from this review showing that individuals experiencing acute emotional distress have difficulties labelling and expressing their emotions. Some self report measures may also require levels of insight, reflection and metacognition beyond the capabilities of that individual at that time or they may be influenced by current mood difficulties or have a self participation or self presentation bias (Aldao et al., 2010). Therefore, we need to consider carefully what is being measured. Is emotional distress and the management of it, as understood by the participants, that is being measured or the understanding of the researcher. Whilst neither position is untenable carrying out qualitative research to check out the participants understadning would go some way in clarifying the answer to this question. he qualitative study investigating emotional distress in young adults (Mortorell-Poveda et al., 2015).

1.3.5.3 Functional approach

The body of literature reviewed here was notable in that how an individual used strategies to reduce their emotional distress was measured by functional or behavioural outcome such as the difference between those who have suicidal ideas and those who attempt suicide (e.g. Zlotnick et al, 1997). Whilst the practice of linking emotional distress to specific symptomatology is a categorical and, perhaps, a pragmatic approach to research, it does not address the underlying issue that people having difficulties in managing their emotions is evident across all forms of mental health difficulties (Cole & Deater-Deckard, 2009).

The functional approach also misses the developmental and social contexts within which emotion distresstakes place. Considering in day to day life an individual interacts with a number of family members, friends or acquaintances, all of whom can cause an emotional reaction within that individual, it is curious that only a handful of papers in this review considered how emotional distress is associated emotion regulation strategies within interpersonal relationships (e.g. Adrian et al., 2009; Nock& Prinstein, 2005; Schulz et al., 2005; Sim et al., 2009).

1.3.5.4 Lack of context

By utilising predetermined quantitative measures, the assumption that all individuals experience particular emotions and distress in a universal way overlooks the subjective experience of the young person and that the presence of certain factors do not necessarily always cause distress (Phares and Compas, 1990). Indeed, little consideration is made regarding what individuals consider to be a 'normal' and tolerable emotional state. Arguably, there is no definitive indicator of whether an emotional response is adaptive or maladaptive in response to emotional distress because this largely depends on contextual factors (Sloan,& Kring, 2007) and is perhaps best understood as on a continuum (Boyle, 2011). Expressing and maintaining positive emotion may be equally important to an individual's clinical outcome and experience of distress (Feng et al., 2009).

By ignoring the fact that the effectiveness of regulatory strategies depends on the specific nature of the emotional experience (Feng et al., 2009) and

employing reductionist techniques there is a danger of ignoring the individual's perspective of their own internal states. For example, emotion regulation is discussed as a desirable and having the primary purpose of reducing distress within the literature yet that may not be the understanding of the individual themselves. As the goal of clinical intervention is to reduce distress (Sloan & Kring, 2007) research should be expanded to incorporate the individual's subjective experience and understanding of emotional distress (Cooper et al., 2010; Zeman et al., 2007).

Of key importance here, is this lack of developmental context within research. Given the growing interest and the importance of addressing emotional distress in clinical interventions (Ehrenreich et al., 2007) it is surprising that the majority of research on how individuals respond to their distress has mainly involved normative or clinical adult samples (Alink, Cicchetti, Kim, & Rogosch, 2009) Mental health difficulties in adulthood often stem from difficulties observable in childhood and adolescence (Daughters et al., 2014; Kim-Cohen et al., 2003; O'Connor, 2011, Zahn-Waxler, Klimes-Dougan, & Slattery, 2000) and within clinical research there are notable discrepancies between adolescent self report and conceptualisation of emotional distress in comparison to parents, teachers and professionals reference. Furthermore, differences in the intensity and level of distress has been found between adult clinical samples and adolescent clinical samples.

1.3.6 Discrepancies in the shared assumption and measurement of emotional distress between adults and adolescents

In terms of differences between emotional distress in adolescents and their adult counterparts there are a number of discrepant findings. For example, in their meta analytic review, Aldao et al. (2010) identified that age played a role in the relationship between psychopathology and emotion regulation difficulties. Specifically that adults samples showed a stronger association and reported use the use of maladaptive problem solving strategies than the children/ adolescent samples. This is perhaps indicative of a difference in how young people respond to and understand their experience of distress compared to adults. For example, in comparison to their adult counterparts, adolescent suicide attempters have been found to have significantly higher behavioural dysfunction including more frequent self injury, number of self injury types and

more expressed anger os proposed problem solving strategies (Zlotnick, Wolfsdorf, Johnson & Spirito, 2003).

In a review of psychiatric treatment for children, Target and Fonagy, (2005) have noted that measures to assess symptoms demonstrate poor correlations between children and adolescents their parents, teachers and professionals. Within adolescence there is often a desire to under report socially undesirable behaviours (Hankin, Roberts, & Gotlib, 1997; Trimpop et al., 2006) and, combined with the finding that those surrounding the young person may not notice internalising difficulties with the young people also denying externalising problems (Target & Fonagy, 2002), these discrpeancies are not perhaps suprising. However, they do exist and the hypothesis for this discrepancy proposed in this study is that a) the application of adult based measures and self report items are inappropriate to use with adolescents and b) this is because of the developmental differences that exist within adolescent population in comparison to adults.

For example, take the assessment of rumination in clinical adolescent samples where measures normed on adult populations have been used e.g. the adult rumination scale (RSQ: Treynor, Gonzalez, & Nolen-Hoeksema, 2003). In one study the RAQ predicted onset of major depression in 496 adolescents as rated by clinicians (Nolen-Hoeksema, Stice, Wade, & Bohon, 2007) yet in another study of 168 adolescents it was unsuccessful at predicting the onset of major depression when rated by both clinicians and mothers (Burwell & Shirk, 2007). With such discrepancy in findings, this highlights how a tool designed to reliably assess depression in adults is not translatable to adolescent populations. How levels of emotional distress are described by adolescents and rated by others is not yet consistent is and reiterates the need for a examination of their descriptions and understanding of distress to consider this.

Target and Fonagy, (2002) propose that illness symptoms and distress in children and adolescents should be measured in consideration of normal developmental processes which are unlikely to be taken into consideration in adult normed measures. The extent to which participants can accurately self report on their emotions and emotions regulation strategies is disputed (Aldao et al., 2010; Robinson & Clore, 2002) and, as noted above, self report measures normed for adults require levels of insight, reflection and

metacognition that may well be beyond the capabilities of a young person at that particular point in their development.

In quantitative instruments that may not have been properly formulated to address adolescent life situations e.g. adapted from adult instruments[4] (Wettergren, Mattsson, & von Essen, 2011) there are no mechanisms to check out their understanding of emotional distress and the measures young people take to avoid or reduce it. Therefore a qualitative study to examine how young people describe and understand emotional distress would enhance our current understanding.

1.4 Adolescence and the relevance of developmental tasks

In trying to understand emtional distress in young people, adolescence is a key developmental stage to focus research on as it is proposed to underlie a successful and pivotal transition to adulthood (Zimmerman & Cleary, 2006). In addition to usual life stressors, individuals have to negotiate greater variability in intra and interpersonal difficulties. As Fonagy, Gergely, Jurist,, & Target (2004) discuss, an individual has to integrate not just their own, but the thoughts, feelings and drives of others on a day to day basis thus involving multiple emotions and as a result, multiple attempts to regulate and manage them.

An adolescent's understanding of their emotional distress can been considered as an 'exploratory map' (Williams & Healy 2001, p. 465) where, in the context of new information and experiences, *'in seeking meaning, individuals may hold a variety of explanations [of their distress] simultaneously, or may move rapidly from one belief to another'* (Williams & Healy 2001, p. 473). This model was developed examining the health beliefs of adults referred to community mental health teams for the first time for depression. Grounded theory was used to anayse interview data and provide insight into the subjective description of the participants. Participant's perceived causes of their illness were social in nature and centred on the concept of the 'self' and how external (others) and internal

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[4] A multitude of questionnaires have been utilised that have been developed in non clinical adolescent populations that, arguably by necessity, have reduced descriptions of difficulties in emotion regulation and require them to be rated on a sliding scale (strongly agree to strongly disagree) e.g. Emotion Regulation Questionnaire (ERQ; Gross, & Jon, 2003) and the Difficulties in Emotion Regulation Scale (DERS: Gratz, & Roemer, 2004).

(self) factors had influence on the development of the illness. What the authors also noted, however, was that participants moved between meanings within the interviews and proposed that rather than a fixed 'explanatory model', the beliefs individuals have about illness should be considered as a transitional 'exploratory map'. Williams and Heaaly (2001) go on to consider how the active attempt to make sense of experience by seeking its cause highlights the importance of explanations to individuals. Therefore, by framing an adolescents understanding of their distress as an exploratory map, it makes sense to consider the unique and multiple developmental and emotional demands that are placed on adolescents that might factor into how they account for, describe and understand their distress.

Christie and Viner (2005) suggest there are four primary challenges to the adolescent period namely the achievement of biological and sexual maturation, the development of a personal identity, the development of intimate sexual relationships with an appropriate peer and the establishment of independence and autonomy in the context of the sociocultural environment. These challenges, however, are different across the time frames of early, mid and late adolescence and incorporate biological, psychological, cognitive and social processes all of which have known associations with emotional distress in this developmental period.

1.4.1 Developmental tasks: Biological

In terms of puberty, it normally starts for both genders in early to mid adolescence (approx 10 - 14 in girls and 11 to 15 in boys) and marks the start of the individual developing a sexually mature adult body. It has also been postulated that the hormones associated with puberty can have a role to play in the manifestation of depression in young people (Angold & Rutter, 1992) although it still remains unclear as to whether puberty is a causal mechanism in its own right (Angold, Worthman & Worthman, 2003).

Furthermore, relative timing is considered an important factor in puberty whereby being out of sync with majority of others elevates an individuals' risk of negative outcome (Angold & Cpostello, 2006) with the onset of puberty either early or later than peers has been noted to have significant psychological and social effects (Christie & VIner, 2005). Early onset of puberty in boys has been

associated with increased self esteem in boys but lower self esteem in girls whereas later development lowers self esteem in boys but has no significant effect on girls (Christie & Viner, 2005).

It can be surmised that puberty is a difficult life stage to negotiate with the individual having relatively little control over their development. Increased emotional distress has been associated with an onset of puberty that is out of synchronization with peers yet little is known about how it might affect an individual's understanding of their distress.

1.4.2 Developmental tasks: Psychological and cognitive

Ongoing developmental growth in the frontal lobes (Galvan et al., 2006) gives rise to the development of complex abstract thinking throughout the period of adolescence. Inhelder and Piaget (1958) proposed that formal operations begins around the age of 11 years and through the cognitive development of verbal abilities the process of abstract thinking and higher order reasoning begins to replace more ego centric thinking. In addition, during adolescence there are expected improvements in memory, attention, processing speed, and organisation.

In terms of its relatedness to emotions and emotional distress, new research suggests that frontal lobe development continues on into an individual's mid 20's (Woods et al., 2006). Due to this ongoing development adolescents are believed to utilise and rely on the amygdala to process information and is the area in the brain that controls emotions. This is in contrast to adults who use their frontal lobes, the centre for reasoning and language, to respond to most situations. As a consequence, not only are adolescents more likely to react quickly and more impulsively, they are less likely to have the language to express how they are feeling (Chamberlain, 2009). This can lead to them experiencing both their own emotions, and those of others, as confusing and difficult to interpret. The literature examining clinical adolescent populations has already demonstrated individuals having difficulty in labelling, understanding and expressing their emotions when distressed yet we do not know if and how young people actually understand and describe this process within the context of their emotional distress.

Furthermore, having to manage many more developmental tasks without the fully matured prefrontal cortex, the area where executive decisions and ethical or moral behaviour is mediated, makes it more difficult for the individual to balance impulsivity, instinctive reactions and rational thought. Thus adolescence is defined as period where young people are more likely to experience fluctuating levels of distress and interpersonal difficulties (Wolfe, 2011)

In relation to this idea of emotional distress is the construct of metacognitive knowledge. The ability of the individual to reflect on their own thoughts, feelings and behaviours develops throughout adolescence and permeates their problem solving, planning and decision making processes (Weil et al. 2013). It is how individuals develop their response patterns to situational experience and has been linked to a number of psychological disorders e.g. depression (Papageorgiou & Wells, 2001) and anxiety (Wells & carter, 2001). Introspection about own mental states developmentally occurs before ability to mentalise mental states of others (Goldman, 2006) and as Spada, Nikčevič, Moneta and Wells, (2008) comment, 'metacognitions are believed to play a fundamental role in influencing the choice of maladaptive coping strategies' (p. 1173). They go on to outline three particular forms of metacognition implicated in psychological distress; 1) negative beliefs about worry concerning uncontrollability and danger, 2) cognitive confidence and 3) beliefs about the need to control thoughts. The coupling of this with abstract thinking contributes to the adolescent developing their psychological sense of self, or personal identity.

In relation to emotional distress, having an awareness of the strategies required to reduce their distress may require a higher meta cognitive level than adolescents have at this developmental time (Eisenberg, Spinard, & Eggum, 2010) and young people might not be able to employ certain regulation strategies due to the ongoing frontal lobe development. Their ability to demonstrate executive control and reign in impulsivity may also not be fully developed (Steinberg, Dahl, Keating, Kupfer, Masten, & Pine, 2006) suggesting that their descriptions and understanding of emotional distress may be excaerbated, impacted by or contingent on these developmental factors.

1.4.3 Developmental tasks: Social

An increase in social demands and the reorganisation of relationships to spend more time with peers than family also increases stress experienced by young people during adolescence. The beginning of strong peer identification begins in early adolescence and increases throughout teenage years to incorporate sexual social relationships and the desire to have intimate relationships. Working in parallel to this is the transition away from and emotional separation from parents with the achievement of social autonomy expected by late adolescence[5]. It is a developmental process considered essential for normal development (Blos, 1967).

Separating the self from others, however, increases an individual's developmental vulnerability due to a reorganisation of the self and a substantial jump in maturation. Peer relationships subsequently become even more important during this stage (Levendosky, Huth-Bocks, & Semel, 2002) and although many will be temporary and exploratory, many will last and become permanent sources of influence. As more weight is placed on social qualities, adolescents begin to value the positive opinions of others which are key in the development of self concept and self esteem (Ikiz & Savi Cakar, 2010). In addition, peers become the providers and recipients of social, emotional and practical support that can facilitate reflection within adolescence (Chen, Cohen, Johnson & Kasem, 2009; Schofield & Beek, 2006) and these relationships are hypothesised to help an individual negotiate a successful transition to early, middle and late adulthood.

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[5] Whilst social autonomy is not necessarily the primary focus of this research, the author acknowledges that these expectations are based on a western conception of adolescence, as indeed are the majority of expected 'developmental tasks'. The privileging of autonomy and individuation (Freud, 1948) is not necessarily replicated in families from different cultures. For example, familial ties are given primacy and considered the most important relationships across the lifespan in a number of cultures such as India (Seymour, 1999) and Bangladesh (Stewart, Bond, Abdullah, & Ma, 2000) . Indeed, interdependence is crucial to self identity (Seymour, 1999) but can make the developmental tasks of adolescence equally challenging (Larson & Wilson, 2004).

Within clinical samples, social support has been posited as a protective factor with respect to emotional distress in terms of moderating the impact of stress in adolescents with psychotic disorders (Henry & Coster 1996), facilitate improved outcome in first episode psychosis (Mattsson, Topor, Cullberg & Forsell, 2008), reduce conduct disorder and depression in children (Appleyard, Egeland & Sroufe, 2007; Cole, Martin, Powers & Truglio, 1996) and moderate levels of adolescent depression (Piko, Kovacs & Fitzpatrick, 2009; Sheeber, Hops, Alperty, Davis & Andrews, 1997; Wright, Botticello & Aneshensel, 2006).

Furthermore, the difficulties in social relationships have shown strong correlation to emotional distress in adolescence. Perceptions of peer rejection during childhood has been significantly related to subsequent mental health problems in young adulthood (Roff, 1990), peer victimization in adolescence has been linked to maladaptive development (Hawker & Boulton, 2000) and also functions as a source of continuing stress for its victims. Poor social support has been associated psychopathology in adolescence and adulthood (Bergeron et al., 2007, Cohen, 2000; Muller & Lemieux, 2000; Parker & Asher, 1987; Sroufe, Duggal, Weinfield & Carlson, 2002; Ystgaard, Tambs & Dalgard, 1999), increased hospitalizations (Cohen, Hammen, Henry & Daley, 2004; Huang, Sousa, Tsai & Hwang, 2008; Lamb, 1982) and heightened sensitivity to distress (Onwumere et al., 2009). Moreover, low social support has also been associated with adolescent borderline personality symptoms (Winograd, Cohen & Chen, 2008) and low ratings of quality of life in obsessive compulsive disorder (Hou, Yen, Huang, Wang & Yeh, 2010).

Whilst these findings are helpful in demonstrating that achieving social tasks in adolescence is key to development and that difficulties negotiating these tasks are associated with emotional distress, we do not know if this understanding is shared by the individuals experiencing distress.

1.4.4 Conclusions

So why examine how young people describe and understand emotional distress? Firstly, measures used to assess adult levels of distress have been found to be inconsistent when applied to adolescent clinical populations (Aldao et al., 2010) and unlikely to factor in developmental factors unique to the period

of adolescene. Second, differing levels of emotional expression have been found in adult and adolescent clinical populations (Zlotnick et al., 2003).

It is proposed here that the developmental factors outlined above are a potential reason for these differences. Where developmental tasks are delayed, interrupted or problematic, increased levels of emotional distress have been found in young people experiencing mental health difficulties. It makes sense, therefore, to propose that examining emotional distress in adolescence should be considered within developmental processes (Target & Fonagy, 2002). By exploring how young people describe and understand their experiences of emotional distress we may find evidence that elaborates how these tasks, unique to this group, play a role in their conceptualisation of distress.

Before this can happen, however, a final consideration will be made in this chapter with regards to clinical intervention as there are difficulties in translating research knowledge into clinical practice.

1.5 Translation of knowledge

Roth and Fonagy (2004) make a clear distinction between the efficacy of intervention, as measured in research trials, and its clinical effectiveness in routine practice. The privileging of randomised control trials within meta analysis, where clinical opinion paper or case studies have the lowest weighting, is evidence of this gap between research evidence and clinical practice (Parry, Roth, & Fonagy, 2004) where the technical sophistication of research trials could be argued to over regulates therapy content and underemphasises the freedom of action available to individual clinicians and clients. So let us turn our attention to current clinical practice for those experiencing emotional distress.

1.6 Clinical intervention for individual's experiencing mental health difficulties

Roth and Fonagy (2004) demonstrate that psychotherapeutic interventions have shown considerable effectiveness for treating adult psychopathology where emotional distress is constructed as a key diagnostic criteria within the vast majority of mental health diagnosis (American Psychiatric Association (DSM 5), 2015; Kring & Werner, 2004). This therapeutic work focuses on strengthening and empowering the individual with skills related to coping with,

managing and regulating emotional responses (Mennin & Farach, 2007). A convergence towards viewing emotions as functional, regulatory and involved in multiple interpersonal processes with has led to therapeutic intervention increasingly incorporating more integrative approaches (Mennin, 2006; Mennin & Farach, 2007). Such examples include dialectical behavioural therapy (DBT, Linehan, 1993), emotion focused therapy (Greenberg, 2002), brief dynamic interpersonal therapy (DIT: Lemma, Target, & Fonagy, 2011) and mindfulness based therapy (Segal, Williams, & Teasdale, 2002).

It is important to note, nonetheless, that complex, historically 'treatment resistant' mental health difficulties such as personality disorders, complex PTSD, and co-morbid presentations still remain difficult to treat successfully within clinical interventions (Ruscio & Holohan, 2006). Mennin and Farach, (2007) propose that emotions are emerging as a 'superordinate factor' within mental health illness (Brown, Chopita, & Barlow, 1998) and perhaps an avenue for addressing the ongoing complexity of emotional distress.

It cannot be assumed that interventions that work for adults will translate well to children and adolescents (Roth & Fonagy, 2004). Recent reviews of clinical interventions with children and adolescents has noted that the evidence base is not robust and mainly considers the efficacy of cognitive behavioural intervention for a wide range of mental health difficulties including anxiety and depression (Fonagy et., 2015; Gowers & Bryant-Waugh, 2004; Ollendick & Shirk, 2012,), eating disorders (Fairburn & Harrison, 2003; Pike, Walsh, Vitousek, Wilson, & Bauer, 2004) plus internalising and externalising disorders (Kazdin & Weisz, 1998).

What has become increasingly apparent is the need for adolescent intervention efficacy to be understood in terms of the mastery of developmental tasks and psychosocial issues central to adolescence (Fonagy et al., 2015; Kreipe et al., 1995). Considering the ongoing physical and psychological maturation that occurs within this developmental period this is perhaps not surprising. For example, ongoing frontal lobe development may preclude the ability of the young person to engage in therapy requiring metacognitive proccesses. Similarly affected by frontal lobe development might be the young persons ability to even engage in therapeutic work, particualrly if they are struggling with impulsivity.

The current evidence base poorly supports such distinctions but there is some work existing. interpersonal therapy for adolescence (IPT-A) has been shown to improve depressive symptoms, improve social functioning and problem solving skills in adolescence (Mufson, Weissman, Moreau, & Garfinkel, 1999). Similarly, mentalization- based treatment for adolescence (MBT-A) is another intervention that works with a young person to understand and develop their mentalizing skills and the role it plays in their sense of self worth, identity, emotion regulation and impulse control. It has currently demonstrated efficacy when used with adolescents who self harmed (Rossouw & Fonagy, 2012). In a similar vein, an adolescent mentalization based integrative therapy (AMBIT: Bevington, Fonagy, Asen, Target, Dawson, & Malik) developed to address the needs of young people with complex, chaotic and co-morbid difficulties via a team based multi modal approach and practice.

However, an qualitative investigation into the subjective understanding of how young people experience distress, accessing the very services in which these interventions and models can be found, has not yet been completed. As developmental and contextual variables are noted to affect the effectiveness of clinical intervention leading authors have called for research incorporating these developmental and subjective experiences of distress to ultimately aid future therapeutic success with adolescents experiencing emotional distress (Kriepe et al., 1995; Ollendick & Shirk, 2012; Target & Fonagy, 2005).

1.7 Chapter conclusions

Despite evidence suggesting emotional distress is integral in the definition, development and maintenance of childhood and adolescent mental health difficulties and subsequent diagnoses (American Psychiatric Association, 2013; Sloan & Kring, 2007; Vasey & Dadds, 2001) there is a notable lack of studies investigating emotional distress in clinical adolescent populations (Scott Brown & Wright, 2003). No study to date has investigated how adolescents talk about and understand their experiences of emotional distress.

So what has been learned so far?

1. Emotional distress is a poorly defined construct in clinical research both in adult and adolescent clinical samples, with very few studies investigating this latter group. As a construct, it has been formulated as

both an outcome from dysregulated emotion but also as a possible factor in the cause of emotional dysregulation. Clinical models focus on the attempts of individuals to manage their distress and try and help them, through a variety of therapeutic interventions, contemplate and regulate their emotions, emotional distress and associated symptomatology. Despite this, certain forms of emotional distress remain difficult to treat and within research there remains a lack of consideration to the developmental tasks of adolescence within the context of their emotional distress

- Predominantly quantitative methodology has been used with little uniformity of measures used. The self report nature of these measures have also drawn criticism due to their focus on functional outcome (e.g. reduction in symptomatology), their lack of context and the inappropriate use of adult normed measures with clinical adolescent populations. There is one study that has explored young adults understanding of emotional distress in relation to how they cope with it but research specifically examining the construct of emotional distress from the subjective descriptions and understanding of adolescents themselves has yet to be conducted.

1. Adolescence is a challenging developmental period where individuals face multiple, complex developmental biological, social and psychological tasks to navigate a success transition to adulthood. It is proposed that discrepancies found between how adults and adolescents rate and manage their emotional distress may be due to navigation of these tasks and the associated pressures they place on a young person. Consequently exploring how an adolescent describes and understands emotional distress and relate it to their internal and external experiences of distress will be of interest in how it relates to what is already known in research and what is practiced in clinical work.

1.8 Rationale

These conclusions highlight a number of gaps in the current clinical literature. Firstly, there is very little quantitative and no qualitative research examining emotional distress conducted with adolescents accessing mental health

services. The challenges of applying adult normed measures on clinical adolescent populations makes it difficult to gain an understanding of an individual's subjective experience and description of distress. As Groleau, Pluye and Nadeau (2007) state, *'the exclusive use of quantitative methods in mental health research presents certain limitations which lie in the subjective nature of mental health problems and related behaviours' (p.731).* Specifically that this methodology concerns itself with the measurement of distress rather than gaining a description of it.

The one qualitative study has, however, highlighted the importance of understanding how individuals experience emotional distress. Mortorell-Poveda et al. (2015) uncovered that young adults understand themselves to be responsible for their distress and that only they can manage to resolve it. Whilst this is specifically in relation to how they cope with distress, like the quantitative research that predates it, by examining young adults narratives explaining their reasoning for using particular coping strategies and resources, these authors have been able to provide a much richer understanding of how these strategies relate to an individuals experience of emotional distress. This understanding within clinical adolescent populations has yet to be explored.

Secondly, clinical practice is evidence based and, as yet, young people have not had the forum in research to provide an explanation of their subjective understanding of emotional distress. It is proposed in this study that due to the unique developmental challenges faced by adolescents and the increased demands on managing the emotions of themselves and others (Fonagy et al., 2005), adolescent employ an 'explanatory map' (Williams & Healy, 2001) in seeking meaning from the experiences of emotional distress. Therefore a qualitative exploration of young people's descriptions and understanding of emotional distress will provide an opportunity to enrich our understandings of potential commonalities in how young people experience of emotional distress.

Therefore, to address these gaps, the following question was examined in this thesis:

1.9 Research question

How do young people accessing mental health services describe and understand emotional distress?

Chapter 2 - Methodology

2.0 Methodology

This study utilised a cross sectional qualitative design to explore how young people accessing mental health services describe and understand of emotional distress in a sample of adolescents attending a Tier 4 CAMHS inpatient unit in London.

2.1 Epistemological considerations

For research to be as transparent a process as possible Holloway and Todres (2003) have emphasised the importance of researchers making their epistemological positions clear. To this end, this researcher takes the epistemological position of a 'critical realist'. This is neither objective nor constructionist in ontological stance, rather it recognises that all observations in the world are fallible and underlined by the constructivist principle that we each construct our world based on our own perceptions of it. Within qualitative research, the assumed objective reality is observed through the subjective lens of both the participant and researcher through the tool of conversation (Howitt, 2010). As Charmaz, (2006, p. 130) comments, a constructivist approach in research *'places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants'*. It is proposed, therefore, that knowledge, must be recognised as context dependent and that because our observations are fallible, so too are our constructions of the world. In efforts to try and see the world as 'it really is', critical realists must acknowledge the theory laden nature of their observations, that knowledge can only ever be approximate, never exact, using multiple fallible perspectives to aid their understanding.

2.2 Method of analysis

It has been argued in the first chapter that quantitative research in this field makes a number of assumptions that arguably prohibit a fuller understanding of the subjective experience of young people experiencing emotional distress. The findings of qualitative research, however, have also received criticism and have been argued as less generalisable than quantitative methods. In answer to this Woods (1996) has argued that qualitative methods generate new ideas and theory that become available to researchers to test and apply to existing

conceptualisations of a particular issue. Qualitative research has also been criticised for a lack of transparency and procedure (Higginbottom, 2004) so the application of rigour and validity have become advocated within the field (see Yardley, 2000) and more commonly applied.

In terms of trying to gain a understanding of how an under accessed and difficult to reach group of service uses understand and describe emotional distress, qualitative research has a number of benefits that perhaps outweigh the lack of generalisability. It has been proposed to facilitate investigation of phenomenon that is difficult to quantify (Willig, 2008) and can enable researchers to explore and develop an understanding of young people's experiences (Thompson & Harper, 2012) by answering the questions of 'how' and 'what' (Green & Throgood, 2010). By being more exploratory and focused on concept discovery, definition and development, qualitative methods have been argued to generate a deeper and rich understanding of human experience and are valuable in a way separate to quantitative methods (Lieber, 2009). Furthermore, considering that the voice of young people is often marginalised in research (France, 2004), qualitative methods are participant led "...*in the sense that they allow participant-generated meanings to be heard"* (p. 15, Willig, 2008).

2.2.1 Thematic analysis

According to the researchers epistemological position an inductive thematic analysis (TA) was selected as the method to analyse the data. TA is a method used to identify, analyse and report themes within a data set where inferences are made regarding both meaning and process (Braun & Clarke, 2006). It is often portrayed as a foundational method of qualitative analysis; indeed, Boyatzis (1998) argues that it is a fundamental core tool underlying many forms of qualitative methods.

By not belonging to a pre-existing theoretical framework, TA allows the researcher flexibility to examine the data generated both in terms of exploring the way in which individuals make meaning of their experiences and the broader context that is imposed on these meanings (Braun & Clarke, 2006). Arguably this allows for the emergence of unanticipated findings (Barker, Pistrang, & Elliott, 2002) and lends itself well to complex and sensitive issues.

Pertinent to the importance of involving young people in research (France, 2004; Kirby, 2004), is that TA ascribes to a participatory research paradigm with participants as collaborators (Braun & Clarke, 2012) where in inductive TA is where themes are linked to the data themselves (Patton, 1990) underlying its suitability as a method exploring process rather than testing hypotheses (Willig, 2008). Finally, Braun and Clarke (2006) have highlighted its suitability as a method for informing service provision in addition to its accessibility to researchers with little qualitative research experience.

2.2.2 Other analysis considered

When considering qualitative methods for this research both Interpretative phenomenological Analysis (IPA) (Smith, 1996) and grounded theory (GT) (Glaser & Strauss, 1967) were considered.

IPA (Smith, 1996) was considered with its aim of exploring the personal and social world of the individual in detail (Smith & Osborn, 2008) yet also still considering the relationship between researcher and participant (Willig, 2008). It is based on the assumption that people will try and make sense of their experiences and is closely linked to phenomenological epistemology (Smith and Osborn, 2008).

There are a number of versions of GT (Glaser & Strauss, 1967) but there is a consensus that it aims to produce new theories 'grounded' in empirical data rather than being developed *a priori* to data collection. It has aspects of a sociological approach, focusing on social processes, and incorporates coding and the generation of broader themes within the data (Willig, 2009).

TA, IPA and GT all share similarities in their aims of representing a view of reality through the identification of patterns within data. However, TA is not bound to one particular epistemological position or theory, nor does it attempt to develop a 'theory' (Braun and Clarke, 2006) allowing for a larger range of considerations to be made and the generation of potentially unanticipated insights. The aim of this research was to examine how a sample of young people described and understood emotional distress rather than trying to make sense of their experience per se or the sociological processes involved. Moreover, the aim was to examine data *across* the sample and to have a broader focus than one of the individual experience. Indeed, whilst recruitment

was from one service, it is not expected that the population examined with be homogenous with expected variations in age, gender, mental health difficulty and experience of mental health services. The greater flexibility of TA, therefore, was felt to be the best fit in terms of the question being asked of the research.

2.2.3 Rigour and validity

Whilst TA is a process that has no pre- existing coding frame, Braun and Clarke (2006) rightly point out, *"..researchers cannot free themselves of their theoretical and epistemological commitments, and data are not coded in an epistemological vacuum"* (p. 12). In fact, a common misinterpretation when conducting analysis is that themes 'reside' in the data waiting to be discovered, but as Ely, Vinz, Downing and Anzul, (1997) comment, *"If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them"* (p.206). A rigorous TA should therefore acknowledge and incorporate this element of reflexivity examining the researchers own contribution as an active participant within the research process.

To ensure the quality of this research four flexible and open ended principles, suggested by Yardley (2000) to assess qualitative research were adopted. In efforts to provide a guide for quality in qualitative study, the author suggests; 1) sensitivity to context; 2) commitment and rigour; 3) transparency and coherence and 4) impact and importance. The enactment of these principles is evaluated in the discussion chapter.

2.3 Research context

The research and recruitment of participants was initiated during the researchers second year of clinical psychology training during a 12 month specialist placement at a Child and Adolescent mental Health Service (CAMHS). All participants were attending a specialised Tier IV CAMHS adolescent unit that provides assessment, care and treatment for young people aged between 13 and 18 years with severe psychological, behavioural and emotional difficulties. The unit provides two services where the participants for this study were recruited; 1) a day programme service (with 13 spaces) offering an intensive therapeutic programme including individual, group and family

therapy, school, art expression and recreation group and 2) an inpatient unit (with 13 beds) which offers the same intensive therapeutic programme as the day programme but for those individuals who cannot manage in the community due to the high levels of distress and difficulties they are experiencing. Each individual has their own programme tailored to suit their specific needs where the aim for all adolescents is careful reintegration into the community focusing on school return and the facilitation of positive family and peer relationships.

2.4 Ethical Approval

NHS ethical approval was obtained on 22nd May 2014 (ref: 14/LO/0616 – see appendix 1) and local Research and Development approval was received on 1st August 2014 (ref: 2350 - see appendix 2). Ethical approval from the University of East London was obtained on the 2nd April 2014 (see appendix 3) and UREC approval was given on 3rd June 2014 (see appendix 4).

2.5 Sample size

Qualitative research focuses on any fewer research participants in comparison to quantitative research (Mason, 2010) and instead aims to delve more deeply into subjective experience. Glaser and Strauss (1967) argued for the concept of saturation to be the end goal of qualitative research where the collection of new data does not contribute anything new to the current analysis. However, Strauss and Corbin (1998) comment that what constitutes 'saturation' in a data set is itself a subjective construction and point out that the more familiar a researcher makes themselves with their data and analysis there is always the potential for new codes and themes to become apparent. They suggest that perhaps researches should consider that they have reached saturation when further analysis becomes counter-productive whereby the new information no longer adds anything to the analysis, again a further subjective interpretation by the researcher alone.

Arguably, the notion of saturation, regardless of the definition, whilst helpful on a conceptual level does not provide specific guidance for estimating sample sizes that will provide enough information for such saturation (Guest, Bunce, & Johnson, 2006). Due to the time constraints placed on a professional doctorate thesis and subsequent limitations on recruitment time it is helpful to read Charmaz (2006) who highlights that the aims of the research should guide

study design. Therefore, for studies that are smaller but with "modest claims" (p.114), saturation may be achieved more quickly than where they have ambitions of generalisability. Furthermore, in a review paper for the National Centre for Research Methods, a sample size of between six and twelve was suggested for qualitative research with groups considered valuable and under accessed (Baker & Edwards, 2012).

2.6 Identification of potential participants

Participants were identified through their key workers, psychiatrists, clinical psychologists or team members involved in their clinical care at an arranged multidisciplinary meeting to identify potential participants. Each individual was assessed for their suitability to take part in the research by discussion with their care team.

2.6.1 Inclusion criteria

- Any young person attending the Tier 4 adolescent inpatient unit.

- If the young person was legally detained in hospital they were still eligible to be considered for participation in this study. Detention itself was not an exclusion criterion.

- Young people must be English speaking.

2.6.2 Exclusion criteria

- Young people who are unable to give informed consent.

- Young people with a moderate to severe learning difficulty.

- Any young person experiencing thought disorder or acute psychosis.

- Young people on my clinical caseload

2.6.3 Limitations of inclusion/ exclusion criteria

By using the above criteria there were a number of limitations placed on the study. Firstly, by utilising the exclusion criteria it can be argued that already difficult to reach young people are further marginalized and their experiences of emotional distress are not heard. Not recruiting from my clinical caseload not only reduced the pool of recruitment but also excluded a sample male

participants from the research who could have added valuable insight, particular in terms of gender related conceptualizations of emotional distress.

The inclusion criteria, whilst left deliberately open to be as inclusive of young people within the service, focuses on a particular group of adolescents experiencing mental health difficulties and emotional distress sufficiently severe to warrant to need for specialist inpatient and day programme CAMHS provision. Adolescents accessing any level of CAMHS involvement are arguably experiencing emotional distress and would have been suitable for inclusion, however, for pragmatic recruitment and ethical application purposes, this study focused on the adolescents experiencing what has been deemed high enough levels of emotional distress to warrant tier 4 CAMHS input.

2.7 Approach and recruitment

In terms of approach, through close consultation with the clinical team, the research was introduced informally by team members and potential participants were given an invitation letter (see appendix 5) and information sheet (see appendix 6) outlining the research in greater detail.

After the information sheets were handed out, individuals were given approximately one week to consider their participation providing them with the opportunity to speak to family, friends or the clinical team about their involvement in the research. They were then formally invited by the author to take part in the research and sign the consent form (see appendix 7).

Due to the nature of the difficulties young people were experiencing it was not always suitable and/ or appropriate to involve parents in their clinical treatment or involvement in research. An example of this was where parents were no longer involved in the care of their child due to issues around abuse or neglect and where young people had specifically asked for their parents to not be informed of any aspect of their ongoing care. When this was the case both the team and researcher assessed each participant under 16 using the 'Gillick principles' (UKHL 7, 1985) for their ability to consent taking into consideration their age and level of understanding for capacity to consent to the research. This involved a team discussion about whether the individuals' key workers felt the young person had sufficient maturity to understand what would be required

of them and the emotional demands that may be placed on them by an interview exploring emotional distress.

If deemed that they were 'Gillick competent', the researcher spoke to the individual about the issue of parental consent for those under the age of 16 and explored the young person's choices regarding the decision they were making to provide informed consent themselves and the demands that taking part in the research may place on them. It was made explicit at all times that participation was voluntary and if they decided not to take part or withdraw at any time their care would not be affected in any way. Participants who decided to take part signed a consent form and were given a copy. The author was responsible for retaining the original consent form.

Where it was appropriate to approach parents/ guardians, they were invited to the meetings between the researcher and potential participant where they had the opportunity to read an information sheet (see appendix 8) and sign a parental/ guardian consent form (see appendix 9) in addition to the young person signing their own assent form (see appendix 10) .

Recruitment was conducted over a two month period from August to September 2014. Out of 26 young people in the service, 14 were identified as suitable for inclusion (see figure 1). 6 young people declined to take part so a total of 8 young people were recruited into the study and data was collected through individual interviews lasting 30 to 60 minutes.
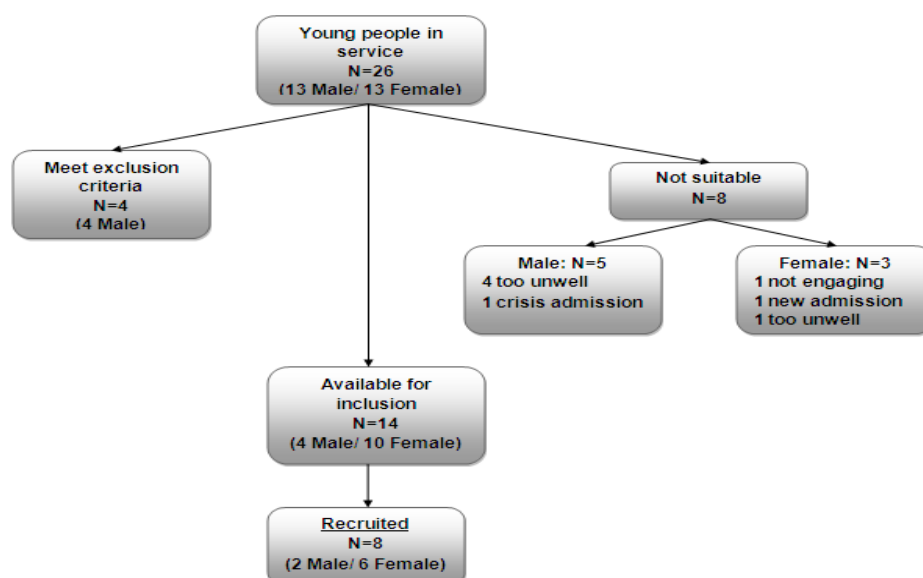
Figure 1: Recruitment flow chart

2.8 Participant demographics

Basic demographic information to describe the population is provided below in table 1. By describing individuals under the pseudonym used in the analysis, it is hoped that this demographic information will enrich the readers understanding of the participants, particularly when considering the analysis.

Table 1: Basic demographic information

Pseudonym of participant	Demographic details
Rachel	A 15 year old, white British female who had been with the service for 5 months. This was her first admission and followed a suicide attempt. She had diagnoses of depression and PTSD with ongoing self harm.
Claire	A 14 year old, white British female who had been in the service for 5 months. This was her first admission and she had a diagnosis of depressions with psychotic features with ongoing self harm and multiple suicide attempts.
Lucy	A 16 year old, white British female who had been in the service for 9 months, This was her second admission and she had multiple diagnoses of depression with psychotic features, PTSD, ongoing self harm and previous suicide attempts.
Emma	A 16 year old, white European female who had been in the service for 7 months. This was her first admission and followed a suicide attempt. She had a diagnosis of depression and ongoing self harm.
Anna	A 16 year old, white British female who had been in the service for 5 months. This was her first admission and she had a diagnosis of depression, ongoing self harm and had previously attempted suicide.
Paul	A 17 year old, white British male who had been in the service for 10 months. This was his first admission and he had a diagnosis of obsessive compulsive disorder and depression.

Steve	A 16 year old, black African Caribbean male who had been in the service for 1 month following a suicide attempt. He had a diagnosis of depression.
Jo	A 16 year old, white British female who had been with the service for 4 months. This was her first admission to the service and she had diagnoses of depression, PTSD and ongoing self harm.

2.9 Procedures

Individual interviews were conducted on site at the Tier 4 service. This ensured that individuals could access their clinical team as well as the researcher to discuss any issues that might have been raised during the course of the interview.

2.9.1 Choice of interviews as qualitative method

Two particular qualitative methods were considered for this study; focus groups or in depth individual interviews. Focus groups were considered due to their ability to facilitate meaningful and shared experience discussions within a group. However, in light of the possibly sensitive discussion that might take place when young people would be asked to talk about the understanding and experience of emotional distress, it was felt that this forum may either inhibit a young person's discussion or lead to an over arousal of distress for the group as a whole. This latter possibility had, in fact, been seen in other group discussions within the service and it was a clear concern that I raised and discussed with the team when designing this research.

Interviews were the second method considered and, ultimately, utilised. Arguably interviews are more time consuming, resource intensive and involve the researcher as part of the instrument (Kvale, 1996). Specifically that they have to be well trained in how to respond to any situation that may arise in the interview to avoid bias or privileging their own agendas. Fortunately, being in clinical training and working within the service where recruitment was based provided this training. It also allowed me to set up interviews within the context

of the service thus facilitating the containment of any potential distress caused by the interview process.

Despite these challenges, I felt that the interviews would afford me greater flexibility and the opportunity to probe and follow up answers from the participants. Interviews would also allow interviewees to check what was meant by questions, ask questions back and give them a chance to challenge the agenda that they feel I might be privileging. They have also been described as the best means to explore reasons and interpretations for particular phenomenon, the crux of my research question.

2.10 Ethical aspects

Interviews were carefully set up so participants felt as safe as possible to speak about their experience. The process of interviewing and distress management was discussed before the interview commenced (e.g. offering breaks). At the end of the interview each participant was given the opportunity to discuss any issues arising from the interview and a chance to be debriefed. Furthermore, the way the service was organised, a member of the individual's clinical team was available if the young person indicated that they wanted further support.

2.11 Self - Reflexivity

As part of research process and using reflexivity I made every effort, under Yardley's (2002) 'sensitivity to context' principle, to be mindful of the inherent power imbalance between the researcher and the participant and how this might have affected the research process. There were a number of ways this imbalance was present and I will outline them below, the reflections I had regarding them and the decisions I made because of them.

2.11.1 Power and the dual role

During this research I held a dual role as both a researcher and as a clinician embedded in the team. Both the team and I were concerned that young people I already had on my caseload might not feel able to decline participation in the research if approached so we decided to keep the roles as delineated as possible. Consequently this was made an exclusion criterion for the research and no young person from my clinical caseload was approached to take part in the research. In addition, with research interviews sharing similarities with

clinical questioning it is also important to reflect on the interactions with participants (Parker, 2005) as this can influence the power dynamic between myself and the young person.

By being part of the overall clinical team I still potentially represented part of the system within which the young people found themselves. Some of the young people taking part had been sectioned so whilst they were given the choice to take part in the research, they were not necessarily given the same choice regarding their treatment. This imbalance of power regarding choice is particularly pertinent when considering the set up of the interview process. Specifically, that I made the decision that I would privilege the safety of the participants and informed them that if harm to self or others was discussed within the interview I would inform their clinical team. In an effort to keep this as transparent as possible, I explained how this process would work; that I would discuss with them (the participant) what my concerns were and who I would be talking to on their team and what I would be disclosing. I was aware that this potentially replicated an experience of powerlessness for the young people and may have left some individuals reluctant to disclose certain aspects of their emotional distress but I felt that this was an acceptable limitation to this piece of work with respect to the ongoing safety of the participants. This scenario was actually played out across two interviews where the participants expressed a serious wish to harm themselves. Once the interview had finished, and utilising my dual role within the team as a clinician, I explored their intention to hurt themselves further. I then walked them through the safeguarding process and discussed with them what my concerns were, who I would be talking to on their clinical team and invited them to attend this meeting which they both did.

Whilst I set the interviews up with the necessary confidentiality clauses and tried to make the participant as comfortable and at ease as possible, the fact that I was a member of the clinical team simultaneously could well have led to a number of young people 'holding back' in all discussion, not just disclosure of harm or risk to self and others. A possible reluctance to talk about any aspect of emotional distress is particularly relevant when considering how the young people in this study reported that the sharing of information between professionals a difficult mechanism to accept within services. However, from the themes that have been constructed in this study, I feel a sense of containment

was provided as participants were mostly forthcoming when discussing negative feelings towards the treatment they had received from services. Furthermore, half of the participants described their motives for taking part as wanting to help other young people in a similar position through contributing to the research process.

2.11.2 Relationship to the question

Exploring distress in a young person was integral to my concurrent clinical work and perhaps demonstrates a partisan interest on my part to investigate the construct further. It also highlights the risks outlined by Kvale and Brinkman (2000) whereby a research interview can become a therapeutic process. I would argue, however, that the skills required to facilitate a meaningful and data rich interview are similar to those necessary to build a therapeutic relationship and facilitate conversation in clinical work.

Each participant took part in one interview that was in-depth and open ended. Two broad questions were used to encourage the co construction of a narrative between the researcher and the participant thus facilitating the evolution of the researcher's understanding rather than beginning from an assumptive position. The idea was to begin all interviews with the same question;

> *'I'm interested in hearing about what you understand about the term emotional distress and what your experiences have been?'*

2.11.2.1 Consultation with young people

In trying to address the power dynamic between myself and the potential participants, and following the advice given by Kirby (2004) on involving young people in research as collaborators and partners not just participants, I consulted a group of service users at the unit to discuss this question. Feedback was that the question was too general and not direct enough. We generated alternatives which were incorporated into the development of an alternative first question of;

> *'What I'm trying to understand is how young people understand emotional distress. So if I said to you somebody was experiencing emotional distress, what do you think would be going on for that person?'*

Following the answer to the questions, the young people fed back that it was then appropriate to ask the original question asking what their experience of emotional distress had been. After this question, follow up prompts were used according to the principles of qualitative interviewing (Charmaz, 2006) e.g. 'can you tell me more about that' with further prompts used to target the individuals autobiographical memory (see interview schedule in appendix 11).

2.11.3 Limitations of the interview schedule

I was aware that due to the open ended and limited number of questions within my interview, each interview could have taken any number of avenues depending on the participant, their experiences and their willingness to discuss these experiences. It must, therefore, be pointed out that my original question and interest of their experiences was with regards to emotional distress so the follow up and probe questions I used privileged this interest and could have prematurely ended conversation that could have provided a meaningful alternative analysis of how the young people understood and described emotional distress.

2.12 Equipment

The interviews were recorded using a digital recording device and then transcribed and anonymised and made ready for coding. After transcription, all digital recordings were erased to maintain confidently.

2.13 Confidentiality

Anonymity was assured by assigning each participant a code. These codes and consent forms were kept in a locked cabinet. The researcher transcribed all of the interviews and all identifiable information was anonymised. On the consent form participants were asked to give permission for anonymised quotes from their transcripts to be used. Only the researcher, supervisors and examiners had access to the transcribed material. Data was only accessed via a password on a computer, and will be erased after five years.

2.14 Transcription

Each interview was conducted and ranged in length from 30 to 60 minutes and were not transcribed until after every interview had been conducted. In terms of

transcription method, it has been suggested that the convention used should be pragmatically suited to the analysis (Edwards & Lampert, 1993). As Braun and Clarke (2006) suggest, there is no one way to conduct thematic analysis therefore no specific set of guidelines exists for this particular method. Nonetheless, a verbatim transcription of the interview is a minimum requirement and as such, each interview was transcribed using conventions suggested by Banister et al. (2011) and following the 'Jefferson 'Lite' principles (Potter & Wetherell, 1987) to make the transcripts easier to read whilst also providing given basic interactional information (such as the interviewer's questions and responses, 'erm'). Talk was made into sentences with conventional textual punctuation but no details were made as to the tone, volume or emphasis of the conversation. All interviewees were given pseudonyms and any further names, places, hospital wards or services were anonymised (see appendix 12 for the conventions used).

2.15 Data Analysis

Thematic analysis was selected to analyse the data. Whilst considering the analysis it must be acknowledged that the ideas, beliefs and understanding were not the same across all the young people with some expressing more views than others. These views, however, were considered with equal importance when developing the themes and sub themes which were selected on the basis that they encapsulated the most important elements from *across* the data (Braun and Clarke, 2006)

Consistent with Yardley's (2000) guidelines to conducting and demonstrating good qualitative research, the six phases ascribed to the analytic process of thematic analysis (Braun and Clarke, 2006) were followed and outlined below.

2.15.1 Familiarising oneself with the data

The first stage in qualitative data analysis is familiarising oneself with the data where the most advantageous start is with the researcher conducting and transcribing the interviews. This has been argued as the preferable approach to ensure important information is not omitted (Riessman, 1993) and means that this phase begins at the earliest stage of data collection. This process afforded me the opportunity to achieve an in-depth engagement with the data.

Once transcription was complete (having been checked back to the audio recording) each interview was read so that I could make notes on my initial thoughts. It was then re-read in what Braun and Clarke (2006) describe as in an 'active' way whereby I began to search for meaning within the data and look for patterns. Initial, and subsequent, thoughts and ideas were noted in the margins on transcripts (see appendix 13 for an example).

2.15.2 Generating initial codes

Following this first stage, a more formal coding process was initiated. This involved organising the data into meaningful groups (Tuckett, 2005) with as many codes generated as possible to allow for as robust an analysis as possible. This coding process was completed in conjunction with my initial notes and codes were noted in the margins of the transcripts[6].

After each interview had been initially coded, coded excerpts from across all the transcripts were collated and checked back against the assigned code (see appendix 14 for coded excerpts across transcripts[7]). From this, a list of codes was generated, often referred to in literature as a 'codebook' (see appendix 15).

2.15.3 Searching for themes

This third phase moved the analysis to a broader and more interpretive level (Boyzatis, 1998). I began to consider my initial codes and their relationship to themes and subthemes within them; some combined together to form themes or subthemes, some became themes or subthemes themselves, others, that did not appear to fit this initial analysis, were kept to one side (labelled as miscellaneous) to consider as the analysis continued.

I needed and utilised visual maps for this process, writing codes on to post it notes and then moving these about as the analysis progressed (see appendix 16). Once this stage was completed I had a provisional list of 16 themes (see appendix 17).

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[6] More than one code was given to an excerpt if appropriate.

[7] For all excerpts (across analysis and for illustration purposes) surrounding data was included to avoid losing context (Boyatzis, 1998; Bryman, 2001)

2.15.4 Reviewing themes

I considered this to be the refinement process in this analysis. Before considering the themes across the entire data set, I first reviewed each theme in relation to the coded extracts. Where excerpts did not fit or form a 'coherent pattern' (Braun and Clarke, 2006), the theme was either reworked, a different theme was created, the coded excerpt was moved to a more appropriate theme or subtheme or ultimately discarded. The result of this can be seen in thematic map 1 (see appendix 18). Repeating this process saw themes and subthemes further merged, divided or discarded which is evidence by thematic map 2 (see appendix 19).

At this point, it felt appropriate to move to the second level of analysis considering the data set as a whole. Here I reflected on the validity of individual themes but also if they provided an accurate representation across the data. I made further revisions here to produce a final thematic map (see appendix 20). As an example of a revision, I felt that the subtheme (in map 2) 'avoidance' could be moved into 'self harm' and that 'self harm' should be renamed 'self harm as a coping mechanism'. I also reconsidered the theme 'emotions are dangerous' and merged it within the theme of 'lack of agency' to better reflect the data. Finally, the labels for each theme were revised to reflect each aspect of emotional distress being considered e.g. isolation was renamed 'Impact of emotional expression: Isolation'.

2.15.5 Defining and naming themes

Having completed my final thematic map I then further defined my themes and subthemes by explaining what I thought was interesting and also what was relevant to my research question (see appendix 21). This also helped me to consider the heterogeneity of the themes as a final analytic process.

2.15.6 Producing the report

This last stage of analysis is detailed in the next chapter where themes and subthemes have been explained and given context and meaning with the use of quotations taken from the interviews with the young people. The relevance of the report to the existing literature and current clinical practice is outlined in the discussion chapter.

Chapter 3 – Analysis

3.0 Presentation of results

This chapter will examine themes and subthemes (see appendix 20 for diagram and table 2) in more detail with meaning and context provided by excerpts from the transcripts. In light of this small adjustments have been made to the text to improve readability of the quotes (Parker, 2005). This includes using square brackets for the inclusions of text for explanation purposes e.g. [text] and (...) to indicate where words have been omitted. Pseudonyms have been given to each participant and I will use the word 'Int' to refer myself as the interviewer. Finally, I have used descriptive terms such as 'many' or 'a number of' to indicate responses of the participants.

Following this chapter will be a discussion considering the interpretation of these findings, the relation of them to the existing literature and clinical implications.

Table 2: Themes and sub themes following thematic analysis

Themes	Subthemes
3.1 Experience of emotional distress: Emotions are uncontrollable	*3.1.1 Emotions are uncontrollable* *3.1.2 Hopelessness*
3.2 Impact of emotional expression: Isolation	*3.2.1 Rejection by others* *3.2.2 Risk of relationships* *3.2.3 Fitting in*
3.3 Management of emotional distress: Self regulation	*3.3.1 Self harm as a coping mechanism* *3.3.2 Talking as helpful* *3.3.3 Disguise of emotions*
3.4 Reaction to emotional distress: Service provision	*3.4.1 Response of professionals* *3.4.2 Young people's experience of the service*

3.1 Experience of emotional distress: Emotions are uncontrollable

This theme encapsulates the young people's reported experience of a lack of agency within the context of emotional distress where they feel they have relatively little ability to control their emotional states often resulting in a sense of hopelessness described vividly by the sample. This theme is therefore represented and explored within two sub themes; 1) emotions are uncontrollable and 2) hopelessness.

3.1.1 Emotions are uncontrollable

This sub theme reflects the young people's experience of their own emotional states that, within the context of their ongoing distress, had an unpredictable and often dangerous quality to them. Many described highly volatile emotions of which they felt they had no prior warning of, like Claire:

> Cos my mood changes a lot as well. The way I describe it is like a crazy rollercoaster because it takes forever for me to get to the top and all of a sudden I go down really quickly and then it's like crazy loop the loops, up down, up down. (Claire)

The use of further analogy was made, such as 'a ticking time bomb' (Emma) when referring to the build up of emotional distress and the uncontrollable and often described, inexplicable, expression of distress. As Paul discusses:

> I'll just be erm the average person and be a bit pissed off like it just depends on what the situation is. Then rarities, I just kind of lose it (...) I feel angry and I don't know it just feels, I feel like I'm bursting with energy everywhere and I just can't concentrate which pisses me off. (Paul)

Feeling as though they are being controlled by their emotions rather than being in control per se was a subject evident in many transcripts,

> I do experience emotions but they never feel like mine, they feel like they've been given to me. I dunno, because everything feels like a game, it feels like my [emotions] are trying to get a reaction out of me. (Anna)

This was not only in terms of the young people being passive recipients of their emotions but also as driven to perform certain behaviours or take certain actions outside of their perceived control. As Rachel comments when describing emotional distress:

> (...) Having emotional distress can make you self harm and do things that you didn't want to do. And I think that emotional distress can also make you suicidal, there's so much going on that you feel like you have no one to talk to – it can get to the point that you just want to die to get rid of it all. (Rachel)

Steve also speaks about how one of his emotional states controls his behaviour:

> [I would like to] control my anger from releasing itself and yeah, causing me to do something bad or something. (Steve)

Contingent on this idea of emotions as uncontrollable was a vulnerability that participants described whereby, for some, distress would manifest itself in a physical way (e.g. hearing voices) and they felt they had very little choice about harmful behaviour either towards themselves or others. Often self harm was spoken about as a way to try and regain perceived control of their situation but that it was not their choice to do it. When Claire describes what happens when she is distressed, she comments on this:

> Claire: Erm, sometimes I get angry, sometimes I get upset and yeah and usually when that happens it triggers voices as well so.
>
> Int: And what happens when you hear voices?
>
> Claire: They usually say to me that I have to do what they say or your family's going to get hurt or we're going to hurt your family. So usually it would be I'd have to cut myself, hurt somebody else and then if I don't usually do that then they will like make me do something even worse like try and kill myself.

Harm towards others was spoken about in relation to young people not feeling as though they had control of their emotions and that a physiological reaction takes over triggering a behavioural response that may endanger their sense of safety and the safety of others. As Lucy in describes her experience of emotional distress:

> It just happens, like I could be just sitting there and the next thing you know like, everything goes dizzy and then I'm gone and I can't get out of it. And then when I come out (...) my heart starts beating really fast and I can't breathe and shit and I'm like what? And then when I'm angry I get really frustrated and I can tell cos I start like tensing and I can't think straight and all I want to do is hurt myself and overdose and punch people and kill people. (Lucy)

3.1.2 Hopelessness

All participants described a sense of hopelessness in the context of the emotional distress they had been experiencing. For the majority of young people there was an ongoing discussion about an unknown future in the context of not knowing any other way to be or feel other than the distress they experience as familiar. As Claire comments:

> (...) I was saying to like the doctors here, like they were saying do you want to change. Thing is, this may sound weird, but because I'm so used to feeling like this I'm, you know, because when I went to CAMHS they said that what I've been experiencing and describing is depression so I've had depression since I was eight years old. (...)I don't know. At the minute it's a bit hard to picture the future. (Claire)

A number of participants also spoke about previous treatment and a sense of being 'unhelpable' where their distress cannot be changed making it difficult to think about or avoid thinking about their future,

> I've done so many different things but none of it stops it. It makes me just think well this is it. My dad tries to help but can't. (...) I don't think about the future, I just don't. I'm going college in [Month] which is really funny on some level because I don't even particularly want to be doing it, I don't want to do anything. (Anna)

A sense of hopelessness in the ability of professionals to help was also prevalent for a number of young people. As Rachel points that when talking to professionals:

> (...) Like, and it's just quite confusing as well cos like when you're talking about [distress] you can't get your own mind around it even when you're going through it your like 'god, I don't get it' and it's like when [professionals] people say to you, 'try to explain it, like we don't know' and I'm like well if you don't know then I don't know, then we're both fucked really. (Rachel)

3.2 Impact of emotional expression: Isolation

This theme represents the young people's sense of isolation in relation to the impact emotional distress had on their interpersonal relationships. It is captured by three sub themes: 1) rejection by others, 2) risk of relationships, 3) fitting in.

3.2.1 Rejection by others

All the young people reported experiencing rejection or a dismissal of their emotional distress by significant people in their lives. Jo experienced rejection

and a dismissal of her distress from those who had initially encouraged her to share her feelings. This led to a self imposed isolation and reluctance to discuss her feelings:

> (...) The friends that I used to have - their mum's or dad's wouldn't know, wouldn't get how I was feel and were just 'oh stop pretending this isn't really how you feel' or 'you're only doing this for attention' and stuff. And I was like 'No I'm not'. So I just keep it to myself (...) they always used to say to me 'oh you know whenever you want to talk, we can talk' and when I actually talked to them they were like 'ah this is really attention seeking' and I was like you know what I'm not talking to you about [self harm] again and they were like 'No no, come talk to me, just don't talk to me about the [self harm] you're attention seeking about' and I was like I'm just not talking to you at all. (Jo)

Dismissal of their distress by family members and friends was also evident throughout a number of interviews,

> I didn't tell anyone to start and then I told my sister who told my mum that she should take me to the doctors and then my mum was getting agitated saying no, there's nothing wrong with you, you don't need to go to the doctors, you're fine you're fine. And then she was like, 'I'll take you down the doctors and then you'll make me look like an idiot' and then they referred me to CAMHS and that's when they diagnosed me with depression with psychotic symptoms. (Claire)

Rejection by family members was discussed as often leading to a chain reaction in behaviour. For example, Paul describes running away from the ward after an argument and perceived rejection by his mother:

> I got into an argument with my mum before [I escaped from the ward], like the day before (...) cos she said 'I'm going to go home now and you can stay here [in hospital] where you belong'. (Paul)

A sense of friends rejecting and 'giving up' (Lucy) on them because of their distress was discussed by some young people and how difficult it was to negotiate their feelings towards them in ways to preserve either the friendship or their own sense of vulnerability. Lucy, in particular, encapsulates this and talks about her friend's response to her distress and her subsequent feelings towards them:

> I've already had people give up on me. Like my friends. They've like, obviously I haven't seen them in ages because I've been in here but like I make time for them innit but they don't wanna know. Like they don't even bother with me to ask if I'm fine or come see me but I'll ask them to come see me and they'll be like yeah yeah and then they never

do, they go out with someone else and it's like ok. And then they're like 'oh your always sad and boring' and all this stuff and I was like well thanks and it likes makes me feel even worse. All I did was care for them and shit like that and it shows how they didn't really care they just want to go out and get drunk and take and drugs and shit.

3.2.2 Risk of relationships

Some young people spoke about the risk of relationships where interpersonal sensitivities have developed due to their experience and expression of distress, Reporting that relationships are not always reciprocal in terms of the support and energy given and invested has left some participants wary of allowing themselves to become close to others. As Emma describes:

> I don't necessarily have friends, I have acquaintances. I try not to make friends much anymore cos I've put myself in situations where I always get hurt. (...) it's heartbreaking because you think you can trust someone and then they go and do something like talk behind your back or whatever, and then you just, and then I get upset and start having a go at them and then I get put as the bad one because I had a go at them and then everything gets turned on to you (...). I just get put in a situation where I hurt myself. Not physically but mentally and I just can't risk putting myself in bad places anymore. Because the whole reason, well the majority of the reasons why (...) people might say I'm 'mental' is because of friends or people. (Emma)

Lucy also attends to this struggle:

> Like if someone's nice to me I'm like oh my god oh my god I like them I like them and I'd be like, I wouldn't want them to leave me and I get really attached and I get really jealous and shit like that. (...) I don't know, I don't want to be on my own but I do want to be on my own but I don't know why I do it, it's just like, it's overwhelming and then I'm like they are just using me then I'm like oh I'll just be used so I won't be on my own and then I get really upset when they go away and I just want to kill them and I always want to hurt myself. (Lucy)

When talking about opening up and trying to have an intimate relationship with another, Paul reflects on the difficulties of attempted reciprocity:

> It's kinda, I kinda tried feeling [my emotions] more often cos it was like erm I dunno it was like, for the other young person like I did date, it was kind of they'd ask me how I feel and like I didn't just want to sit there and be like some rock, but I didn't feel anything which used to annoy them (...) I just thought I only know how to switch it off so if I switch it on, if things get too bad just switch it off again (...), it's just not as easy [to switch it off] as I thought it would be. To switch it off again. I switched it on and I started to feeling things kind of thing and then as soon as I did, like then... like basically.. as I said like,

my girlfriend just broke up with me. So as soon as I switched it back on she breaks up with me and it's like, now I'm just kind of a bit all over the place with emotions. And I don't like it at all (...) like you feel betrayed, you feel lost, you feel all these different things so I just don't want to feel them. (Paul)

3.2.3 Fitting in

This sub theme captures the expectations the young people described they felt from other people and society to 'fitting in' and being 'normal'. This perhaps is a reflection of the social challenges facing young people in this developmental period, specifically the growing importance of developing and maintaining peer and romantic relationships. With respect to society and gender roles Paul spoke about his idea that, as a man, he should only be perceived as strong which meant him concealing his emotional states. Even though he considers it normal for others to express themselves, he considers this as demonstrating a weakness within himself. He comments:

> I'm kind of stupid but I have one of those just macho male mentalities, it's just like I can't let stuff affect me, just got to , I don't know, carry on kind of things. If something bothers me I'll just block it out and so not let it get to me.(...) I've kind of always had like that outlook. I don't really want people to think I get upset or struggle (...) it's just something I don't like, being looked upon as almost like weak in a way, I couldn't stand it. (Paul)

A number of young people also commented on the pressure to try and 'fit in' with others in terms of 'normality' and the consequences of not meeting these expectations, an idea encapsulated by Emma when describing the first time she had taken an overdose to stop her emotional distress:

> If I didn't take the overdose, I wouldn't be here, I'd still be at school. I'd be living life with everyone else at school. Maybe not exactly like them, like they'd still be really happy and I'd still be upset but I'd still be a bit more in society, accepted more. I don't know, I think being accepted in society these days, it fucks with everyone's minds. Like there is such a need to be socially accepted it just annoys me like everyone has a need to look like [Model 1], have a body or have clothes like [celebrity 1] or have her bum, I don't see the need in that. And then you're only pretty if you wear the whole of [Make up brand] on your face. I just don't understand and if you have like, if you're straight you're more like accepted. (Emma)

3.3 Management of emotional distress: Self regulation

This theme describes the efforts made by the young people to manage their distress by attempts to reduce, control or disguise it. Three subthemes encapsulate this and are:1) self harm as a coping mechanism, 2) talking as helpful and 3) disguise of emotions.

3.3.1 Self harm as a coping mechanism

Self harm was universally described as cutting and being an individualistic self regulation and coping method to control experiences of distress. To alleviate distress, to 'take it away' (Claire) was the conceptual goal of the young people who engaged in self harm.

> I self harm to cope (...), I know that it is a coping mechanism but it is definitely an addiction, like if I go more than a week without it I get crazy, really crazy... I feel like there is a game being played on me basically and it's, there's a total lack of control you know, somebody's playing games with you and you have no control. And self harm feels like a way of control. (Anna)

Using self harm as a way to express and release difficult emotions was also described by many participants,

> I would bottle all my emotions up and then it would become too much and I needed a way to release my emotions. So I would turn to cutting and overdoses to release, take away and have a different kind of pain. (Claire)

Talking about distress was discussed as difficult with self harm considered to be an alternative to talking about experiences and the associated distress,

> I used to cut myself quite often because of, because I couldn't get the words out (...) because I wouldn't let myself say it so I used to take it out on myself, so I used to hurt myself, I used to cut myself, and try to overdose and hang myself so I wouldn't so I wouldn't so that I wouldn't ever have to say it (right) kind of thing. (Rachel)

Many young people described a disconnect between their mind and body, often referring to dissociative states when distressed,

> (...) there's a complete feeling of unreality you know (...) I get very low and I get very scared cos the worse the dissociation gets the more scared I get. It just feels strange, everything feels strange, I self harm to cope. (Anna)

and self harm was described as their way of reconnecting to their physical selves. It was also spoken about as a way to transform the young persons experience of pain:

> I don't know, it sounds really clichéd like I dunno, it just, you took your feelings and you made them physical like things you can't really feel on the outside you made them so you like you can feel them. (Emma)

Within the context of being inpatients, two young people spoke about the lack of opportunity to self harm as increasing their distress and leaving them 'without any coping strategies' (Anna and Claire) or mechanism to release their distress. In this way, self harm was conceived as a protective mechanism whereby through avoiding, reducing or being able to control distress it 'saved' (Claire and Jo) the participant from an escalation in their actions resulting in suicide attempts or harming others.

There was recognition within the sample that alternative coping methods and less harmful forms of self harm existed but that they had limited use and were less helpful than self harm.

> I've tried like everything else like the elastic band, writing things down in the diary then ripping it up and then [self harm is]... just feels better and then you're like, OK it's a scar, but it makes you feel better. (Jo)

There was an exception to this discourse however, in Emma. She had managed to stop self harm despite continuing distress by changing the way she thought about her life and behavioural choices using a 'treasure' box in her recovery. As she comments:

> (...) then I made a box with little things, quotes and stuff and little toys that I play with when I felt the need to self harm'. (Emma)

3.3.2 Talking as helpful

There was a consensus among the participants that talking about emotional distress was difficult but necessary and that if able to talk about it, discussing their distress helped that individual to share their experiences and 'relieve the burden' (Emma) of distress.

> I used to find it really really hard to tell people how I was feeling. If someone asked asked me how I was feeling I would say 'I'm fine' even if I felt like total shit and wanted

to die (mmm). I'd be like 'oh I'm fine' and no one none ever really saw through it (right) so I was like I said I was fine, they thought I was fine and it got to the point where I wasn't ok anymore. I was like you know I'm not fine, I'm not ok, I've had a load of shit happen, I need to speak to someone about it (mmm) (Rachel)

However, young people reported that they often did not have the words or language to accurately describe their emotions or distress, particularly in the moment of distress,

I find it quite hard to describe how I am feeling. When I am feeling it at that exact moment I can probably describe it but if it's like to reflect on how I felt about a certain time of day I find it hard. (Steve)

There were also comments from the young people reflecting on the need for talking so that others can understand their experiences yet recognising at the same time that this was difficult to do:

Erm, [talking]'s still a bit difficult at times. Part of me at time s is a bit no don't say it they're going to think bad of you and the other part of me is like it's something I've been through, it's something people need to know to help me (mmm) so I can help them understand better, not just keep it on the inside, cos telling people will think differently of me. If they think differently of me then that's their problem cos they're not really, they are, whatever they think of me they think of me, it's not going to hurt me in any way. (Rachel)

Lucy also comments:

I'll tell or talk to staff here sometimes about how I'm feeling but sometimes I can't or it's not the truth but I still try to do it whereas before I wouldn't have talked about it (...) talking to somebody make me feel listened to and understood a bit better like they want to help me. (Lucy)

3.3.3 Disguise of emotions

In all of the interviews there were discussions regarding the hiding of emotional states and distress from others including friends, family and professionals. Even though young people considered it acceptable for others to express their emotion, they expressed a reluctance to do this themselves:

I'd never speak to [my peers] about [my distress] cos no one here knows why I'm here cos I don't want the thing like, cos if they know then they might be able to tell when I do struggle, if I do at any point. I don't want them being 'oh, are you ok, do you need help', like how they ask each other. I don't want that. I'll happily do it for someone else, 'you

alright kind of thing', but I don't want to have to rely on anyone to have to be like that. (Paul)

Young people also reported that they felt that, when they had shown their emotions, their distress had not been taken seriously. Claire comments on this:

(...) most of the days people would think I was the happy one, I'd laugh all the time but really was covering [my distress] up so people would think I was fine (...) I didn't want them to know, I didn't want them to realise I was struggling. When people find out about it they are like 'you're too young to be depressed, you shouldn't be depressed' and I'm like 'oh for gods sake you've got no idea what's going on for me'. (Claire)

Similarly, many of the young people spoke about experiencing judgement or ridicule when they spoke about or somehow demonstrated their distress leading to active attempts to hide their distress in future interpersonal interactions:

Emma: I don't cry but my eyes like build up in tears, I don't cry as much as I used to. I dunno, one of my decisions was not to cry so much.

Int: Why was that?

Emma: I guess cos in school I used to get picked on for, like I'd get picked on and then I'd cry and then I'd get picked on cos I'm crying and they would call me an attention seeker for crying. Yeah and I guess that was kind of the reason I don't cry that much anymore.

Emotions were also disguised in efforts to pretend the distress had gone to ensure discharge from the service. This served a dual purpose for these participants because, in addition, they spoke about trying to disguise or 'block' their emotional distress in efforts to trick or convince themselves that they were going to be OK albeit usually unsuccessfully.

I'm just putting on like a brave face innit like just to get out of here even thought things ain't that good but I need them to be good so I pretend everything is fine and good so I do really start to believe it and then when I'm on my own or something I just feel depressed. (Lucy)

3.4 Reaction to emotional distress: Service provision

This theme describes the treatment and reaction young people experienced from professionals in relation to their emotional distress and expression of it. It is described within two subthemes; 1) Response of professionals and 2) young people's experience of the service.

3.4.1 Response of professionals

In relation to the overarching theme of lack of agency is this sub theme of the response of professionals to the expression of distress by the young person. All the young people described a medical response from professionals when they became distressed where medication, restraint techniques and mental health Act 1983 sections were utilised in response to their upset and subsequent behaviour,

> Last time I was distressed (...) I was put on this section and I was like 'I want to leave I want to leave' and all I wanted to do was go out and kill myself and I was really stressed (...) I was in reception and I was just screaming and I was just standing next to the door and all the staff were around me and I just felt like crying and screaming. And I didn't want them to touch me or come near me, (...) it felt like to me that no one was listening and that I needed to go and hurt myself and like screamed so loud and was throwing myself against the walls to hurt myself and then they all came at me and restrained me to the floor and then I just started crying and screaming. (Lucy)

Some young people acknowledge that professionals were trying to help them but comment on the unhelpful methods used. In describing her most recent restraint in the context of being paranoid about 'a man coming to get me', Claire commented:

> I guess here they like try and help you (...) but I saw [a nurse] with a needle and that was it, I lost it. I was shouting at them, I started crying because (...) this was going to make it worse. And then they injected me. (...). I fell asleep and erm yeah but I've still got the bruises on my knees where they restrained me, and I have a scratch under the arm where they scratched me accidentally. (Claire)

All young people talked about an escalation in their emotional distress prior to receiving treatment from the service and many came through the pathway of being sectioned either by the police or by the medical team. It was described as an intrusion in their lives and an action that usually had negative consequences in terms of forming or continuing relationships with the team. As Paul describes:

> I experienced a few problems then I kind of just went to CAMHS and from there they said about this place and I ended up here. Cos I had like that male macho thing I was like it doesn't matter, I'm fine I'll deal with it but it just kind of, they got really bad, like the problems in my head and I wouldn't talk to [the Doctor] or anyone about it like I'm like I'll deal with it, I've got it, I don't your help, I don't want it and I ended up getting sectioned. (...) There was a lot of anger I guess towards my team, the people here just like, you

think ok it's their job their just trying to help but it's like how dare you come to my home and tell me you're going to try and take me away to that place. (Paul)

There was also a described lack of transparency regarding some of the legal processes where the young people did not know if they had or had not been sectioned. When describing a recent time when she had run away, Jo commented:

I didn't want them to arrest me but they sectioned me to bring me back and I was like 'I don't want to be sectioned'. And they hadn't told me they were going to section me so when I came back [staff] were like 'you're on a section' and that made me more angry as [the police] hadn't told me I was on section so I felt like I had been sectioned. And then I said 'why am I on section' and [staff] said 'oh no you're off it now' and I'm like 'that confused me, you're sending me really mixed signals'. It was just so confusing. (Jo)

In terms of being given medication, a number of young people spoke about this as a first response from staff when they were expressing their distress with some commenting on preferred alternatives. Here, Jo elaborates on her choice of being alone when distressed in light of her previous experience of health professionals where she felt she had received an uncaring, and rather medical, response to her distress:

Jo: (...) some staff, they're like 'oh we really do care about you' and your like 'really you don't. They're like 'oh let's go talk, let's get you some medication to help you calm down'. It's like I don't always want to resolve, result in medication all the time (...) if they really care, they wouldn't just give me medication.

Int: What would they do?

Jo: They would talk to me. Some staff are just like 'here, here's medication and then we'll talk after the medication' but by the time they come to me I'm in bed fast asleep because the medication's kicked in.

Similarly, Lucy spoke about her distress being conceptualised by others as needing medication:

I want some like support and not to feel so alone and like I'm on my own fighting this like when I'm distressed and shit I can have someone there to tell me its OK instead of thinking oh she needs some drugs or something to calm her down or like but like, for someone to talk to or something or go to the gym and get it all out or something. (Lucy)

Further to this, many young people also spoke about the processes and procedures that are intrinsic and necessary within the NHS but feel uncontaining for the individual and leaving them less likely to look for help. Jo spoke about the need for professionals to have to disclose information to colleagues regarding self harm. As she comments:

> They always tell everyone else, that's why I don't want to talk to them. People higher up and then the people higher up come talk to me and I'm like I don't want to talk to you, I trusted my counsellor and now (...) apparently they can't cope with it or they can't deal with it they've sent me you and I don't want to talk to you. (Jo).

3.4.2 Young people's experience of the service

Throughout the interviews the young people spoke about their experience of the service highlighting challenges and both positive and negative experiences. Many young people reported certain aspects of treatment were experienced as a challenge, specifically that of talking therapy, yet the outcome had often been positive, as Rachel explains,

> No one knew what had happened, I hadn't told anyone cos I'd I just felt so disgusted with myself and I didn't want anyone to know. (...) and being here and getting it all off my chest and letting people know and letting people know how I'm feeling and what's been going on with me has been so, it's been a lot of effort and it's been really hard but it is great after you've told someone because someone else knows. (Rachel)

Other young people commented on the relief at sharing their emotions within a therapeutic relationship without fearing judgement,

> (...) now I talk about [my emotions] (...) to [psychologist name] who is like my own personal diary (...), it's nice being able to tell someone something and not be judged, it's just nice to be able to let it out rather than bottle it all up. (Emma)

In terms of less positive outcomes and related to impeding discharges, a number of young people commented on how they felt their levels of distress had not changed,

> Things ain't really different, like I'm not dealing with [my emotions], I more blocking them cos there's things like I know I'm just going to end up in a mess if I don't deal with them but I just don't know how to so I just block them out (...). (Lucy)

Emotional distress was reported by some as still ongoing and there was an expressed reluctance to leave the service. As Paul comments:

> I don't want to go yet. Cos I want, like I just feel like I've just switched everything back on (...) but I'm still all over the place with emotions. I don't, I want to feel like, today I want to just like go back to just me just, flatline, in control. (Paul)

Claire spoke about her anxiety regarding discharge and belief that her experience of the service will be repeated:

> My next CPA is [soon] and (...) I'm scared that if I get discharged then I'm going to go through that whole process where I get sectioned by the police, I get brought back here and I have to go through it all again and I don't want that (...) it's going to happen all over again and I don't want that cos it was bad enough last time. (Claire)

The young people spoke about their paths through the service and the treatment provided for them. For some individuals reflecting on their journey's progression, there was a gradual shift towards feeling as though they could cope with their emotions and distress. When discussing her therapy and treatment, Emma comments on her starting position and how it shifted:

> I was really confused about life in general like what I wanted to do in the future or if I wanted to have a future, if I wanted to stay alive even, I just kept on having thoughts about life in general. The sad thoughts became more confused thoughts. Like distress thoughts like wanting to end my life, they turned more about, turned into like why would I end my life or what is the reason and then I used to look at the reasons and balance it out and it kind of got better from there. (Emma)

Finally, a number of participants reported moving to a position of hope for their future whilst acknowledging that difficulties still exist within their lives:

> It's scary but it's amazing. To know that I've now, like before I didn't think I had a future, I didn't want to have a future, and to now know that I have a future is kind of gobsmacking. I'm not going to say I'm 100%, I'm not going to say I have a perfect life because no one does. But I feel so much better than I did when I first came here. (Rachel)

<u>Chapter 4 - Discussion</u>

4.0 Discussion

This thesis presents a unique insight into the subjective experience and impact of emotional distress from the perspective of a difficult to research service user group of young people experiencing mental health difficulties. This viewpoint from an insider position is a new contribution to the current literature and will be discussed in this section in relation to the research question. Following this will be a discussion of the clinical implications and suggested future work and will conclude with limitations to the work and reflections on the research process. Finally, a concluding summary of this thesis will be provided.

<u>4,1 Findings in relation to research aims</u>

The research question was,

How do young people accessing mental health services describe and understand emotional distress?

Findings will be considered in relation to the two parts of the research question that are:

1. How do young people describe emotional distress?

2. How do young people understand emotional distress?

4.1.1 How do young people describe emotional distress?

The themes and subthemes in this study relate to this question in a number of ways. They highlight the way in which young people felt emotions were uncontrollable, the difficulties they experienced in describing their emotions, the consequences this had on their ability to talk about their experiences and the responses they experienced in relation to this expression of distress.

The theme of 'Experience of emotional distress: Emotions are uncontrollable' highlights how young people spoke about their emotions as uncontrollable. Within this theme, the locus of control is firmly external with young people describing a lack of perceived agency (subtheme 'emotions are uncontrollable') and hopelessness (subtheme 'hopelessness'). Gross (1998) proposes that young people begin to learn how to exert control over the emotions they

experience and research has highlighted the need for young people to take responsibility for making changes in the way they manage distress (Wood, 2009). Yet the understanding of these participants, that their emotions and subsequent distress are out of their control, suggests they position themselves as passive recipients without the ability to effect change. Whilst challenging, it should be considered that this external locus of control is not necessarily a pathological difficulty or one that is unique to this group considering the natural shift from a more external to more internal locus of control as adolescence continues (Chubb & Feltman, 1997).

The second subtheme within this overarching theme of emotional distress being uncontrollable was one of 'hopelessness'. This theme speaks to the young people's belief that neither they nor professionals could help or change their experience of distress. Consistent with previous findings where hopelessness, high levels of distress and less perceived ability to manage emotions have been associated with suicidal behaviour and ideation (Donaldson et al., 1997; Esposito et al., 2003; Orbach et al., 2007) a number of young people commented that their suicide attempts were in response to feelings of hopelessness. What has been added by this research, however, is that young people place this hopelessness within their descriptions of emotional distress being 'uncontrollable' exacerbated by an inability to describe their experiences.

In the theme 'Management of emotional distress: Self regulation', under the subtheme of 'talking as helpful', some young people described not having the words or language to describe or understand their emotional states. This replicates previous findings in clinical adolescent samples (Lambert & de Man, 2007; Sim et al., 2009; Southam-Gerow & Kendall, 2000; Van Rijn et al., 2009) and work examining frontal lobe growth in adolescence where ongoing development is hypothesised to impede a young person's ability to accurately describe or interpret their feelings (Chamberlain, 2009). What is important to consider within this subtheme, however, is not just the confirmation from young people that their emotions are difficult to label and express but also the consequences these difficulties had on how young people were motivated to or able to engage with the service.

Despite talking being framed as helpful by the young people, they spoke about difficulties in engagement with psychology, where the privileging of talking

therapies makes it a daunting task for those who do not have the words to describe their feelings or have a reluctance to do so. Young people also identified a fear of judgment by professionals within this theme underlining the importance of the therapeutic relationship, already associated with the effectiveness of therapy and outcome (Bordin, 1979; Martin, Garske, & Davis, 2000). To this end, the way in which young people reported professionals responding to the perceived uncontrollability of their emotions was mirrored in their reported lack of choice and agency in treatment at times of acute distress.

Within the theme of 'impact of emotional distress' and specifically the subtheme of 'response of professionals', despite young people identifying a desire to have more opportunity to talk about their emotions they described the use of 'disputed'[8] actions such as restraint, sections and medication. Whilst a number of participants reflected on the intentions of the team and that they understood they were doing 'what they thought was best', the use of these actions led to some young people talking about how they felt even less in control of their treatment, were in a worse situation and had even less choice in their treatment having shown their distress to others.

These findings suggest that adolescents describe and experience their emotional distress as an uncontrollable experience and provide narratives suggesting their experience is recursive in nature. Wherein emotions are experienced as uncontrollable by young people, exacerbated by difficulties in elaborating on or describing them and then mirrored by professional responses to the expression of distress. This is inherently different to the current investigation of distress in the literature whereby focus is on how adolescents respond to and try to manage their levels of distress through strategies of emotion regulation. These findings will now be considered in terms of their clinical implications.

4.1.1.1 Clinical implications

The theme of 'Experience of emotional distress: Emotions are uncontrollable' that emerged from the young people's descriptions of emotional distress has a number of implications for clinical practice.

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[8] 'disputed' by the young people

In relation to young people describing emotions as uncontrollable, where their perceived lack of agency relates to both their own experience of distress and the response of professionals, these findings are, perhaps, indicative of the current clinical conceptualization of distress. Where there is the privileging of the medical model over the role of experience across clinical contexts (Boyle, 2011) professionals can often adopt a form of naive realism in terms of what clinical treatment is given.

This perception of distress as uncontrollable may suggest that young people do not feel confident about their ability or capacity to make changes and this may not map onto the understanding of professionals. This finding could be interpreted as showing that discrepancies may arise between the assumptions of the young people and the professionals involved in their care. The former not believing change is possible whereas the professionals believe there can be a change.

That young people experience their emotions as uncontrollable, have difficulties in understanding them and can experience their treatment as challenging or outside of their control are important factors to consider when we know that a majority of adolescents do not seek professional help when distressed (Lee, 2009) and that young people experience difference, between professional language and understanding and their own, as reason to avoid mental health services (Martinez-Hernáez, DiGiacomo, Carceller-Maicas, Correa-Urquiza, & Martorell_Poveda, 2014). The fear of judgement from a professional or a lack of belief in the benefits or efficacy of treatment that have been found in this study have also been noted to increase avoidance of help seeking in adolescents (Martinez- Hernáez et al., 2014). This supports the current intensive outreach models trying to engage difficult to reach groups of young people experiencing distress.

In the theme 'Management of emotional distress: Self management', the difficulties young people reported in being able to describe their distress through language supports current clinical formulation whereby the developmental stage of the individual is factored into the therapeutic engagement, intervention being used and length of proposed treatment. The challenges of talking therapy are considered within this and often models of

intervention are adapted to the needs and level of emotional understanding of the individual.

In terms of clinical implications these findings draw attention to the mostly shared conceptualisation of distress between clinicians and young people. These findings support that discrepancies can exist, however, in how young people and the professionals consider the self agency of young people experiencing emotional distress. Importantly, these discrepancies have been highlighted as something that can prevent engagement with or help seeking from professionals when young people are describing or attemotng to decribe their emotional distress.

4.1.2 How do young people understand emotional distress?

The themes 'Impact of emotional expression: Isolation' and 'Management of emotional distress: Self regulation' suggest that emotional distress is understood by young people as something to be avoided, suppressed or disguised in efforts to engage in, develop or maintain interpersonal relationships despite the high intrapersonal cost to themselves. There are a number of ways this is evident across the themes in this sample.

Under the theme of 'Impact of emotional expression: Isolation' and the subtheme 'rejection by others' a number of participants reported that their attempts to talk about their emotional distress, seek help or try to understand it further were met by rejection from or exclusion by significant others including family and peers. This exclusion from peer groups supports previous findings in clinical adolescent populations where the expression of distress was the given cause for exclusion (Adrian et al., 2009). The subsequent decision reported by some of the young people to withdraw from social relationships in response to these interpersonal conflict also mirrors previous findings (Spirito et al., 1989).

These difficulties within interpersonal relationships when expressing distress are important given the importance of peer relationships and acceptance in healthy adolescent developmental achievement (Chen, Cohen, Johnson, & Kasen, 2009; Walsh, Harel –Fisch, & Fogel – Grinvald, 2010; Wood, 2009). It is also important when considering the possible internal working models of these young people. That their help seeking efforts were rebuffed and their selves rejected is highly likely to maintain an insecure attachment style to interpersonal

relationships leading to possible further over or under arousal and consequential emotional distress.

Highlighting a sense that their emotional distress is understood to be unmanageable and consequently needs to be suppressed is that almost all young people described how their experience of distress affected the reciprocity they experienced in relationships, examined under the subtheme 'risk of relationships'. Current literature points to social support, from family and peers, being a protective factor when individuals are experiencing distress (Newcomb & Bentler, 1988; Reicher, 1993; Stadler, Feifel, Rohrmann, Vermierien, & Poustka, 2010) but the findings from this study suggest that this perhaps needs unpicking further. In terms of reciprocity, Pearlin (1985) suggested that when an individual cannot reciprocate in a relationship, a 'caring debt' develops which can become a major source of stress for that person. Indeed, the low self esteem associated with depressed patients has been found to result in them focusing on the negative side of receiving support (e.g. they will be unable to repay a caring debt) thus resulting in them reporting being less likely to use or accept support (Parry, 1988). Reciprocity in social relationships is particularly emphasized in developmental tasks of peer relationships during childhood and adolescence where individuals feel validation in both offering and receiving support (Kelly & Jorm, 2007).

The majority of young people in this study described a discrepancy between the support they offered to others and what they perceived in return when experiencing distress. This led to some young people describing relationships as a 'risk' and reporting an ambivalence both about the availability of support and seeking it out, findings similar to those of Green, Hayes, Dickinson, Whittaker, & Gilheany, (2002). This perhaps suggest that young people experiencing mental health difficulties struggle with reciprocity in relationships which subsequently impacts on their amount of and availability of social support at times of distress.

Comparable with suggestions made by Butler, Lee and Gross (2007), some young people in this study also reported a reluctance to seek support from others when there was conflict with the socio cultural norms of the individual (Lee, 2009) and is examined in the subtheme 'fitting in'. For example, with

respect to expressing distress, Paul spoke about how his ideas of masculinity dictated his behaviour where he reported feeling that allowing others to see his distress show him as 'weak' echoing previous findings throughout literature where a dominant culture of masculinity is less tolerant of emotional fragility (Horrocks, 1994). Other participants spoke of the need to fit in and conform to the 'norm' within their peer groups or as they felt is represented by the media. If they did not 'fit' they experienced rejection and isolation in the context of their peer relationships.

Explored under the theme 'Management of emotional distress: Self regulation' and specifically the subtheme 'Disguise of emotions', is the decision by the young people to disguise their emotions following the rejection from others following their expressions of distress. This was reported by all the young people in the study and supports current literature where young people have been found to actively mask emotional states from others to achieve social goals (Rosenbaum, & Lewis, 2003) and from themselves in efforts to suppress the impact of their own distress (Southam-Gerow & Kendall, 2000).

In other efforts to manage their emotional distress, all the young people reported using self harm in response to their distress and is represented by the subtheme 'Self harm as a coping mechanism'. This echoes the body of work presenting dysfunctional behaviour, specifically self harm, as a form of emotion regulation made by adolescents to cope with and alleviate their distress (Bergmans et al., 2009; Adams, Overholser, & Lehnert., 1994; Hawton et al., 2012; Nixon et al., 2002; Orri et al., 2014; Zlotnick et al., 2003). Also supporting existing evidence, self harm was reportedly used by a number of participants to transform emotional pain into a physical one (Sim et al., 2009) with three young people describing it as a way to try and avoid their distress.

However, whilst self harm is currently constructed in the current literature as a maladaptive or unwanted action (e.g. Nixon et al., 2002) through talking to these young people it would appear that this is not a straightforward conclusion to make. Many of the young people reported feeling overwhelmed by their emotions and understood self harm to be their only option to protect themselves from further harm e.g. trying to attempt suicide. Some also described the

experience of hearing voices telling them to harm themselves and others thus leaving them feeling relatively powerless when engaging in self harm.

The difficulties caused in interpersonal difficulties following either the expression of distress and subsequent attempts to mask and disguise emotional distress to conform to expectations and not risk rejection by others suggests that these young people experience their distress to be their responsibility. This echoes the findings of Martorell-Poveda and colleagues (2015) in a young adult sample. However, the difference with this group is that,unlike the young adult, they do not have the experience of trust within relationships. Support from family and friends for this sample has not been consistently experienced and has led to young people conceptualizing social relationships, in particular, as risky within which to engage. By becoming more isolated, it could be hypothesized that the consequential affect of not having an active listener to validate subjective experience as found be Martorell-Poveda et al. (2015) impacts on the young person's sense of self efficacy and autonomy.

4.1.2.1 Clinical implications

Considering how the social developmental tasks of adolescence highlight how crucial peer relationships are for an adolescent's identity and sense of self worth, the theme of 'impact of emotional expression: Isolation' has important clinical implications. Indeed, the recursive difficultly of emotional distress in interpersonal relationships was highlighted by the findings of Moses (2010) who found 62% of an adolescent sample who had been diagnosed with emotional or behavioural disorders had suffered stigmatisation as a result of emotion expression that had resulted in friendship losses or transitions.

Perhaps this feeds in to the conscious choice of the young people to 'disguise of emotion' which itself is an important subtheme to consider as suppression of distress has shown significant correlation with depression, anxiety and shame in adolescents (Lanteigne et al., 2012) and increased emotional and mood instability (Schramm et al., 2013). For many young people, previous experience of rejection and in some cases ridiculed, had been internalised into internal working models and was reported as why they deliberately hide their feelings or perceived 'weakness' (Paul) from others. There is a clear distinction described by some young people between the private experience of distress and their

public display which they report as dependent on what they decide is appropriate or acceptable share. These findings support the sociocultural conceptualization of psychological distress and management of personal experiences (Kleinman,1988) within clinical work..

The risk and reciprocity of interpersonal relationships were described by young people as having considerable intrapersonal risk. Social support is considered as an important within clinical intervention yet this study highlights that navigating these relationships for young people experiencing distress is a difficult task. Perhaps this finding draws attention to the reciprocity of relationships with an a young person's network especially when a number of young people spoke about the desire to have support from others motivated them to engage with peers even if these relationships were known by the young person to not be conducive to their wellbeing (e.g. Lucy). Furthering our understanding a young person's motivation to engage in these relationships will continue to aid our formulation of a young person's understanding and experience of emotional distress.

Challenging the assertions made by in the current adolescent literature by Sinclair and Green (2005) that the cessation of self harm behaviour will lead to a resolution in distress, it was found that some young people reported an increase in distress when unable to self harm (e.g. Claire and Anna). They commented that they no longer felt they had any coping strategies and that alternatives to self harm did not reduce their distress. This supports current clinical understanding that self harm has a function (e.g. Sim et al., 2009) but also highlights that self harm is not something young people experiencing distress can easily give up. It makes sense, therefore, that the focus of clinical intervention is on empowering young people by helping them or enabling them to learn new ways to identify and cope with the antecedents of distress and provide viable alternative coping strategies to self harm (Wood, 2009).

The findings of this study also highlight the need for awareness within clinical practice and MDT working how the product of the one behaviour can be understood in different ways. For example, current literature postulates that self harm could be a form of communication drawing the attention of others to the distress of the individual (Orri et al., 2014). However, young people in this study did not describe their motivations for self harm in this way, rather it was

described as a way for them to release their feelings of distress, an internal coping mechanism with an external consequence with often (unwanted) subsequent treatment.

The clinical implications of how young people understand distress relate to their experiences following expression of their distress, the interpersonal difficulties that result and the often high intrapersonal cost of having to be self reliant in their management of distress. These findings that represent the voice of a marginalized group demonstrate that current clinical conceptualizations of emotional distress share many commonalities with young people with the addition of perhaps drawing our attention to the importance of exploring the reciprocity of social and familial relationships for this group.

4.2 Future research

This work has highlighted areas worthy of further exploration. The finding that relationships can be risky for young people when experiencing distress is certainly an avenue that warrants further investigation particularly the impact and importance of social contacts with the young people's networks and the developmental challenges they face at this time. Either peer or familial rejection was experienced universally across the sample which resulted in the vast majority of participants becoming self reliant in their attempts to make sense of their distress. Yet, within adolescence, there is an expectation for these individuals to be building and maintaining peer relationships. Exploring the young people's construction of what is expected in these peer relationships and wider society with regards to the expression of emotional distress would perhaps provide a helpful framework in which to understand their behaviour. .

The young people who spoke of the helpfulness of talking about their difficulties, both to their networks and to professionals, emphasized how long it took them to start talking about their distress and experiences. This perhaps highlights a need to unpick what precludes young people from talking about emotional distress but also what had enables this process to start.

Importantly to identify is the need to conduct research into how professionals understand the distress of young people to identify areas that will inform how services engage with and treat young people. Current literature highlights

discrepancies between how young people, their parents, teacher and professionals rate the emotional distress of that young person. The findings from this research, where young people described unhelpful and medicalised responses from professionals, give further weight to the argument that there is perhaps a conceptual difference in how young people and professionals understand and want to treat distress. This would be of great interest to explore qualitatively with professionals to consider how their and young people's understanding of distress fit together.

Finally, to ensure a mutual understanding of this topic the involvement of young people must move from a tokenistic to real position whereby they move from being participants, to collaborators and partners and are involved at the earliest conceptual point of the research cycle. Moreover, the findings from this study demonstrate the importance of continued clinical research investigating the subjective experience of the individual within the context of their wider systems. Martinez – Hernáez et al. (2014) advocate for the use of qualitative research methods and notes the inextricable link between this methodology and clinical implications. They comment,

"In stimulating reflection by both study participants and researchers, it functions unobtrusively as a form of prevention and as an invitation to young people to engage with mental health care providers and contribute their insights towards improving the accessibility of services" (p.123)

4.2.1 Future methodology

Considering the potential future research, I would anticipate the employment of IPA methodology as a helpful and insightful next step. In their descriptions and understanding of distress, the young people who participated in this study have demonstrated that their lived experience of distress needs further exploration. Personal, interpersonal and social factors such as rejection from peers and family, medicalised responses by healthcare professionals and a culmination of many difficult life events can be argued to form the basis of the young person's description and understanding of emotional distress. However, by gaining a more in depth knowledge of their lived experiences will further enhance our

understanding as to the nature of emotional distress experienced by young people with mental health difficulties.

In this study young people spoke about how they did not necessarily fit in with the expectations of society or tried to conform within gendered roles. This social discourse would benefit from further examiniation particularly using the method of discourse analysis. By analyzing naturally occuring language within this group about their experiences of emotional distress, this sociolinguistic approach could potentially provide valuable insight into the sociopsychological construction of distress within young people experiencing clinically significant levels of distress.

4,3 Critical review

In an effort to provide rigor and validity and keep the process of this work as transparent as possible, the four principles of Yardley (2000) were utilized and are evaluated below.

4.3.1 Sensitivity to context

'Sensitivity to context' requires the researcher to attend to theory, relevant literature, sociocultural settings, the perspectives of the participant and ethical considerations such as the power imbalances that may be occurring within the context of the research. To demonstrate sensitivity to context I conducted a search of the existing literature investigating emotional distress within clinical adolescent populations and this was linked to the under involvement of this client group in research processes. The process of obtaining ethical approval and attendance at ethic committee meetings certainly focused my mind to the ethical aspects of the work, potential impact on participants and it also helped me refine my definitions of terms being used in the work. To highlight the perspective of the participants I conducted in depth interviews and endeavored to support my arguments and conclusions with verbatim quotes.

4.3.2 Commitment and rigour

'Commitment and rigour' necessitates the researcher to have an in depth engagement with the topic, competency in the methodological skills being

utilised and conducting a thorough data collection and analysis. Thematic analysis, by nature, requires an in depth immersion into the data and I have described each stage of the analysis process (see methods chapter) in efforts to show commitment and rigour. In terms of competency, this was my first use of thematic analysis and I have reflected on the process of conducting qualitative analysis in the following section (see 4.6.1). In addition I developed my skills through lecture attendance and reading to develop my analytic skills.

4.3.3 Transparency and coherence

'Transparency and coherence' recognises the need in qualitative research to have clarity and power in the description of the data, to be transparent in methods and presentation, to investigate the fit between theory and method and for there to be reflexivity throughout the process. To demonstrate transparency I have provided detailed examples of each stage of the analysis in the appendices and attending to coherence, I have located the findings in context to the current literature and highlighted where new contributions have been made. In addition, personal reflections on the research process were made and are discussed in the methods section and returned to here, in the discussion.

4.3.4 Impact and importance

Finally, 'Impact and Importance' recognises the decisive criterion by which research is judged, specifically, its theoretical, practical and socio-cultural implications which have been outlined in the first part of this chapter. Furthermore, this work is of clinical relevance both young people and the professionals they work with and because of this, I will be making every effort to disseminate the research findings to participants, the service in which the research took place and wider academic and clinical forums.

4.4 Limitations of the study

From critically reviewing the research, a number of limitations are evident. They will be discussed here and should be considered when examining the findings of this thesis.

4.4.1 Method of analysis

It must be acknowledged that this thematic analysis (TA) and presentation of these findings is just one interpretation and, of course, influenced by both the researcher, as an active participant within the research process, and the research questions. As Foster and Parker (1995) comment, *'the analysis of the material... is a deliberate and self-consciously artful creation by the researcher'* *(p. 204).* However, TA can also be viewed as a foundational method providing useful information for further research. As there is a dearth of literature exploring distress in young people accessing mental health services, this seems particularly relevant.

4.4.2 Methodology

Recruitment took place specifically within a single CAMHS at a single site. Whilst Lavigne and Faier-Routman, (1992) recommend caution when using one site for recruitment due to a possible bias of service characteristics, the aim of this study was not to generate findings that speak across all populations. Rather, the aim was to encapsulate how this particular group of young people described and understood their experiences of emotional distress

Another caveat also concerns the recruitment of participants into the study. The design was for individuals to be identified by their key workers in the clinical team. Whilst the author was in close consultation with clinicians about suitability and inclusion criteria, clinicians may still have only referred those they considered 'stable enough' to take part. This impacted on the hoped for and planned sample size as 8 out of 26 possible participants (31%) were deemed as unsuitable for research by the team. This may also have resulted in a recruitment bias where those with the worst adaptation and most severe difficulties were excluded meaning this sample may not be fully representative of adolescents within this particular Tier 4 CAMHS services. This reflects the challenging nature of child and adolescent research where young people are often acutely unwell and staff perhaps play a protective role that can inhibit the examination of the true population.

4.4.3 Heterogeneity of the sample

One area, however, that was difficult to attend to in this research was the 'noise' of the sample. There were a number of variables within the sample that could have influenced analysis and would certainly be important to explore in further research. One such factor was ethnicity. Three quarters of my sample were white British with one participant being white European and the other black African Caribbean. Although it can be argues that this demographic was representative of the population where recruitment was based, important cultural aspects are likely to have been confounded. Similarly, I am aware that the age range of this sample is relatively large for the period of adolescence and represents a possible multitude of developmental stages. The size of the sample precluded further analysis of this thus not allowing the coding or examination of possible subtle nuances across the data.

4.5 A return to self-reflexivity

4.5.1 Power

I was aware that I carried a dual role when conducting this thesis as both a member of the clinical team and as a researcher. Whilst I tried to address this in terms of only recruiting young people who were not on my caseload, I was aware that the MDT structure of the team and holistic nature of the treatment package on offer within the unit made it almost impossible to delineate these roles for both me and the participants. During the set up if the interview I made every effort to explain my role as a researcher in the room for that particular task but also reiterated my privileging of their safety.

An important responsibility to reflect on was in regards to the procedure of consent. None of the young people who took part wanted their parents involved in the procedure. Whilst the Gillick principle is specifically for young people under the age of 16 (which could be applied to 2 of my 8 participants), I felt the concept underlying it were applicable to all of my participants due to their levels of vulnerability and ongoing risk. I took time, therefore, to explain the research procedure with each participant and any possible effects that I could foresee of taking part in the research. This facilitated interesting discussions with young people seemingly unaware of their ability to make independent choices

regarding participation. I also had to address some difficult conversations, particularly with the two young people under the age of 16 with respect to their relationships with their parents/ caregivers and difficulties therein[9].

This dual role, however, also afforded me of being in a trusted, privileged position where I was able to create a sense of safety around the research. The majority of young people who took part voluntarily commented on how they had found the interview a 'useful space' to think about their understanding of their own distress and the benefit of having no time limit placed on them when discussing their difficulties. This perhaps, again highlights the very real challenges of service provision for children and young people within the NHS where time and staff and service provision constraints are increasing in light of increasing demand for services and financial pressures (Department of Health 'Future in mind', 2015). Arguably this is further disempowering our service users.

4.5.2 The process of qualitative methodology

Utilising a qualitative approach was a novel process for me. I chose this methodology instead of quantitative because I wanted to speak to the young people and attempt to understand distress from their perspective. Whilst I had anticipated that interviews on this subject matter could be difficult for the young people in talking about it and myself in terms of attending to their stories, I had not anticipated the impact of the in depth immersion in the data required by thematic analysis. The multiple readings and coding had a profound effect on me and left me with a genuine admiration of the participants' abilities to be managing as well as they were in the context of many difficult systemic, interpersonal and environmental difficulties.

4.5.3 Research findings

During the write up my research, I found the themes generated a strong sense of empathy within myself for the young people and a real desire to protect them. A particular challenge was the subtheme 'response of professionals' where

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[9] For reasons of confidentiality I cannot comment on what these difficulties were but suffice to say they precluded the involvement of parents in the treatment of that young person.

young people reported experiences of rejection, dismissal and avoidance of their emotional distress by professionals meant to care for them. As part of this professional team I felt a strong sense of shame at their perceived treatment yet grateful at the same time that myself or psychological provision were not included in this within the narratives, However, this 'split' engendered by the descriptions from the young people was quite powerful and perhaps experienced as so due to my dual role. However much I would like to believe that I was not complicit in their treatment, by being a clinician within a multi disciplinary team that is responsible for their care, therefore holding a position of power, young people may have made associations between me and this experience and thus impacted on the research process.

Another theme that I had a strong reaction to was isolation, particularly the subthemes of the 'risk of relationships' and 'disguise of emotions'. I found it very sad to read of the reasons why young felt they had to disguise their emotions yet also surprising to hear of just how big the burden social relationships can be on young people, especially vulnerable young people experiencing emotional distress.

Whilst challenging, I found I actually enjoyed the research process of this thesis, particularly the interviews with the young people. Their descriptions, understanding and experiences of distress gave rise to important considerations that I believe need to be incorporated into clinical practice. This heuristic process, whereby the answers to my research question, evolved from my own clinical formulation of distress, will now inform my future formulations of distress within this particular client group. This process of this thesis and research has also reaffirmed my belief and ambition to continue research with young people, but not just as participants, but as collaborators and ultimately as partners.

4.6 Overall conclusions

Following the assessment of the research process and notwithstanding the limitations, this study has a number of strengths.

The aim of this study was to contribute to the understanding how young people accessing mental health services describe and understand emotional distress. It

is the first study of its kind to explore the subjective experience of emotional distress in an under accessed and under researched population of young people. It represents the voice of an often marginalized group and, through this qualitative exploration of their lived experience, has shown how this maps on to our current understanding of emotional distress in both research and clinical practice.

In terms of how young people describe emotional distress, this study has found evidence that young people experience emotional distress as something out with their control, exacerbated by difficulties in understanding and describing their emotions, leading to a sense of hopelessness and a lack of self agency being re experienced in regards to their treatment from professionals. It supports current conceptualizations in clinical practice that engaging in talking therapies can be challenging for those experiencing emotional distress. It also supports current thinking around cognitive development and that due to ongoing pre frontal development, difficulties in labeling, understanding and therefore interpreting emotion is not uncommon to this group.

In relation to how young people understand emotional distress, this thesis proposes that young people understand it to be their responsibility to manage , despite describing it as uncontrollable, following rejection form others after their expression of it. This self reliance has high intra and interpersonal costs. In addition to this, a key difference between how young adults and adolescents manage their emotional distress is that young people do not describe the same sense of safety and trust within social and family relationships as described by young adults. In fact, their subjective understanding of distress is that it leads to their isolation and self regulation strategies to cope. In terms of clinical implications, these findings demonstrate that current clinical conceptualizations of emotional distress share many commonalities with young people in terms of their self regulation strategies of self harm, talking and disguising their emotional distress. Moreover, they confirm the importance of support from others when experiencing distress but also offer further evidence demonstrating the importance of exploring the reciprocity of social and familial relationships for this group.

To conclude, it is acknowledged that this thesis offers just one interpretation, a 'snapshot', of how a particular group of young people accessing a Tier 4 mental

health service conceptualize their experience of distress. However it does provide a unique insight into how young people understand and experience distress and presents a form of 'exploratory map' that these adolescents use when considering their distress and makes suggestions how the findings could perhaps be incorporated into current clinical work.

As Bowlby (1980) hoped,

„...despite all its deficiencies, our present knowledge may be sound enough to guide us in our efforts to help those already beset by difficulty and above all to prevent others becoming so." (p.442)

Overall, it is hoped that this study has contributed to the current literature and will encourage continued research of distress. As Claire commented in her interview,

> (…) maybe if more people do research on the adolescent brain and how and why emotions change the way they do then maybe people will start to understand a bit more like, you know, what we go through and how we feel.

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6.0 Appendices

Appendices

Appendix 1: NHS Ethical Approval Letter

NHS
Health Research Authority

NRES Committee London - Camden & Islington
Room 002
Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne & Wear
NE32 3DT

Telephone: 0191 4283545

22 May 2014

Dr Rebecca Fisher
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
School of Psychology
The University of East London
Water Lane, London
E15 4LZ

Dear Dr Fisher

Study title:	How do young people accessing mental health services describe and understand emotional distress?
REC reference:	14/LO/0616
Protocol number:	N/A
IRAS project ID:	130752

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting revised documentation]

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager at nrescommittee.london-camdenandislington@nhs.net.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

A Research Ethics Committee established by the Health Research Authority

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.[##IfAdditionalConditions##]

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper		24 March 2014
Interview schedules or topic guides for participants	version 1.0	20 March 2014
Other [Ethical practice checklist]		02 April 2014
Other [REC UEL Letter of approval]		
Other [Summary CV for student]	Katy Berg	20 March 2014
Other [Participant assent form]	1.0	21 May 2014
Other [Researcher risk assessment]		02 April 2014
Participant consent form [Consent form parent/ guardian]	2.0	12 May 2014
Participant consent form [Participant Consent Form]	3.0	21 May 2013
Participant information sheet (PIS) [Parent/guardian information sheet]	2.0	12 May 2014
Participant information sheet (PIS) [Participant information sheet]	2.0	12 May 2014
REC Application Form	Version 3.5 IRAS 130752/591245/1/866	31 March 2014
Research protocol or project proposal	version 1.0	20 March 2014
Summary CV for Chief Investigator (CI)	Rebecca Fisher	20 March 2014

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review
Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed

guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
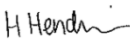
Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

14/LO/0616	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp H Hendr

Mrs Rosie Glazebrook
Chair

Email:nrescommittee.london-camdenandislington@nhs.net

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: Professor Neville Punchard, University of East London

                            ███████████ Research and Development

A Research Ethics Committee established by the Health Research Authority

Appendix 2: R& D Approval Letter

NHS

NHS Foundation Trust

Research and Development Office

Date: August 1st 2014

Dear Dr Rebecca Fisher,

Re: **R&D ref no 2350 – How do young people accessing mental health
services describe and understand emotional distress?**

I am pleased to inform you that the above named study has been granted approval
and indemnity by ███████████ Director of Research and Development
███████████████ You must act in accordance with the
███████████████ policies and procedures, which are
available to you upon request, and the Research Governance Framework. Should
any untoward events occur, it is **essential** that you contact your Trust supervisor and
the Research and Development Office immediately. If patients or staff are involved in
an incident, you should also contact the Governance and Assurance department, in
Goodmayes Hospital, and complete the Incident and Reporting Form, namely the IR1
form.

This approval is valid until 30th November 2014. You must inform the Research
and Development Office if your project is amended and you need to re-submit it to
the ethics committee, if your project is extended or if your project terminates. This is
necessary to ensure that your indemnity cover is valid and also helps the office to
maintain up to date records.

You are also required to inform the Research and Development Office of any
changes to the research team membership, or any changes in the circumstances of
investigators that may have an impact on their suitability to conduct research.

Yours sincerely,

Research and Development Manager, ███████████ NHS Foundation Trust

2350 R&D Approval letter – How do young people accessing mental health services
describe and understand emotional distress?   1 of 2

List of documents reviewed by ██████ R&D Department

██████ Project Registration Form		
Research Protocol	Version 1.0	20th March 2014
Patient Information Sheet	Version 2.0	12th May 2014
Parent/Guardian Information Sheet	Version 2.0	12th May 2014
Consent Form Parent/Guardian	Version 2.0	12th May 2014
Participant Consent Form	Version 4.0	18th June 2014
Participant Assent Form	Version 1.0	21st May 2014
Interview Schedule	Version 1.0	20th March 2014
NHS REC Form	130752/591245/1/866	7th April 2014
Letter from REC	14/LO/0616	8th April 2014
Letter from REC	14/LO/0616	7th May 2014
Letter from REC	14/LO/0616	22nd May 2014
Letter from REC	14/LO/0616	28th June 2014
NHS REC Form	130752/627508/14/823	20th June 2014
NHS SSI Form	130752/631811/6/514/203110/303128	1st July 2014
Feedback form Research Proposal	████████	
Feedback form Research Proposal	████████	
Ethical Practice Checklist		2nd April 2014
University Ethics Approval	████████	
Letter from sponsor		
CV	Dr Rebecca Fisher	20th March 2014
CV	Dr Katy Berg	
CV	████████	
GCP Certificate	Rebecca Fisher	8th July 2014

2350 R&D Approval letter – How do young people accessing mental health services describe and understand emotional distress?   2 of 2

Appendix 3: Ethical Approval from the University of East London

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Katy Berg   **ASSESSOR:** ▮▮▮▮▮▮▮

STUDENT: Rebecca Fisher   **DATE (sent to assessor):** 28/03/2014

Proposed research topic: How do young people accessing mental health services describe and understand emotional distress?

Course: Professional Doctorate in Clinical Psychology

1. Will free and informed consent of participants be obtained?   YES

2. If there is any deception is it justified?   N/A

3. Will information obtained remain confidential?   YES

4. Will participants be made aware of their right to withdraw at any time? YES

5. Will participants be adequately debriefed?   YES

6. If this study involves observation does it respect participants' privacy? YES

7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically?   YES

8. Is procedure that might cause distress to participants ethical?   YES

9. If there are inducements to take part in the project is this ethical?   YES
10. If there are any other ethical issues involved, are they a problem?   NO

APPROVED

YES

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: IA   Date: 2/4/2014

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Katy Berg   **ASSESSOR:** ▮▮▮▮▮

STUDENT: Rebecca Fisher   **DATE (sent to assessor):** 28/03/2014

Proposed research topic: How do young people accessing mental health services describe and understand emotional distress?

Course: Professional Doctorate in Clinical Psychology

Would the proposed project expose the <u>researcher</u> to any of the following kinds of hazard?

1	Emotional	NO
2.	Physical	NO
3.	Other (e.g. health & safety issues)	NO

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: LOW

APPROVED

YES

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **IA**   Date: 2/4/2014

For the attention of the assessor: Please return the completed checklists by e-mail to ethics.applications@uel.ac.uk within 1 week.

Appendix 4: UREC Approval Letter University of East London

EXTERNAL AND STRATEGIC DEVELOPMENT SERVICES
uel.ac.uk/qa

Quality Assurance and Enhancement

03 June 2014

Dear Dr Fisher,

Project Title:	How do young people accessing mental health services describe and understand emotional distress.
Researcher(s):	Dr Rebecca Fisher
Principal Investigator:	Dr Rebecca Fisher

I am writing to confirm that the application for the aforementioned NHS research study reference **14/LO/0616** is sponsored by the University of East London.

The lapse date for ethical approval for this study is **03 June 2018**. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NRES ethical approval and provide a reason why UREC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS ethical approval.

With the Committee's best wishes for the success of this project.

Yours sincerely,

Catherine Fieulleteau
Ethics Integrity Manager
For and on behalf of
Professor Neville Punchard
University Research Ethics Committee (UREC)
Research Ethics Office
Email: **researchethics@uel.ac.uk**

Appendix 5: Participant invitation letter

Participant Invitation Letter

University of East London

School of Psychology

Stratford Campus

Water Lane

London E15 4LZ

Dear

Principal Investigator: Rebecca Fisher, email u1138184@uel.ac.uk, Tel: 0300 555 1156

Study Title: How do young people in mental health services describe and understand emotional distress?

I would like to invite you to take part in a research study. My name is Rebecca Fisher and I am a trainee clinical psychologist conducting a research project for my professional doctorate qualification. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read this leaflet carefully. You do not need to decide whether or not to take part immediately.

Please ask me any questions. You can phone and speak to me on the following number 0300 555 1156 ex 7208. If I am not in, then you can leave a message and I will return your call.

Yours sincerely

Rebecca Fisher (date**)**

Appendix 6: Participant Information Sheet

Patient Information Sheet Version 2.0   12th May 2014

Participant Information Leaflet

Study Title: How do young people in mental health services describe and understand emotional distress?

What is the research about?

I would like to find out about your experience of emotional distress because I would like to hear how you describe it and have experienced it in your own words.

Why have I been asked to take part?

I am asking all people who are receiving treatment in this service to take part in this study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part I will ask you to sign a consent form. The consent form is a way of making sure you know what you have agreed to. If you decide to take part you are still free to withdraw at any time and you do not have to give a reason. If you do decide to withdraw from the research then any personal information you have provided will be deleted from the study. Any information that you have provided that is anonymous will remain in the study, By anonymous information I mean information that no one, apart from myself, would be able to tell has come from you.

The support and help you receive from your team will not be affected if you decide at anytime you do not want to take part.

What will happen next?

If you decide to take part, I will be in touch and we will arrange a convenient time and place to meet at X. I would like to meet with you on two occasions.

At our first meeting I will answer any questions or concerns you may have. During the second meeting I will ask you about your understanding and experience of emotional distress. This will last for approximately one hour.

I will also ask you if the second meeting can be recorded on a digital voice recorder. The purpose of recording this meeting is because the analysis I will use relies on your exact words that you use during the interview. I will listen to and write down what you have said word for word, take out any information that would identify you personally (e.g. names of people), and destroy the recording.

I will show you the recording equipment and demonstrate how it works before starting recording. You are free to stop the recording at any time during the interview. Importantly there are no right or wrong answers. It is your point of view that I would like to hear.

What is the down side of taking part?

It is possible that our meeting(s) may cover topics that are difficult or distressing for you to talk about. If you feel distressed we can stop the interview. You can also take a break at any time.

Will anyone else know that I am taking part in this study?

Yes although if you decide to take part in the study your clinical team will be told that you are taking part. If there is anything in the interviews that you feel would be useful to share with your key worker then we can arrange this for you. If, however, you disclose information that suggests you may harm yourself and/or others this information will be, as per service policy, shared with your clinical team.

In terms of confidentiality the interviews will be listened to and written down word for word. The information will be made anonymous so no one, apart from myself, will know what information has come from whom. This will be done by giving a different code to the information each individual provides. These codes, as well as consent forms will be kept in a locked cabinet. The researcher will write down all of the interviews word for word and all identifiable information will be removed. On the consent form you will be asked to give permission for quotes from your interviews to be used. These quotes will be anonymised

meaning that no one would be able to tell what quote has come from whom. Only the researcher, supervisors and examiners will have access to the written out interviews . Data will only be accessed via password protected files on a computer, and will be deleted after five years.

What are the possible benefits of taking part?

You will not directly benefit from taking part in the research. However, the information I learn from this study will help me plan future research and contribute to the development of new psychological therapies to help understand emotional distress and make sure we are understanding young people like yourself and providing them with what they need in mental health services.

What will happen to the results of the research study?

I will provide you with a summary of the results of the study. The final results and conclusions of the study may lead to publications in scientific journals. You will not be identified in any publication..

Who is organising the research?

The research is being organised by the University of East London.

Who has reviewed the study?

This project has been reviewed and approved by the ethics committee at the University of East London and given managerial approval by the local Research and Development Departments in the North East London Foundation Trust (NELFT). It has also been reviewed and approved by the NRES Committee London - Camden and Islington.

If you have any concerns about the conduct of the investigator or any other aspect of this research project, you are encouraged to contact the study's supervisor Dr Katy Berg, School of Psychology, University of East London, Water Lane, London E15 4LZ Tel:020 8223 4409, k.l.berg@uel.ac.uk
or
Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ, Tel: 020 8223 4493, m.finn@uel.ac.uk

Thank you very much for reading this information sheet and for thinking about this study. Please keep this invitation letter for reference.

Appendix 7: Participant Consent Form

Participant Consent Form Version 2.0   12th May 2014

Study Number:

Participant Identification Number for this project:

CONSENT FORM

Title of Project:: How do young people in mental health services describe and understand emotional distress?

Name of Researcher**:** Rebecca Fisher, email u1138184@uel.ac.uk, Tel: 0300 555 1156

Please initial box

2. I have the read the information sheet dated 12th May 2014 (version 2.0) relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

3. I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

4. I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

4. I understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)   Participant's Signature

…………………………….................   ....

Researcher's Name (BLOCK CAPITALS)   Researcher's Signature

…………………………………………   ....

Date: …………………..…….

Appendix 8: Parent/ Guardian Information Sheet

Parent/ Guardian Information Sheet

University of East London

School of Psychology

Stratford Campus

Water Lane

London E15 4LZ

Principal Investigator: Rebecca Fisher, email u1138184@uel.ac.uk, Tel: 0300 555 1156

Study Title: How do young people in mental health services describe and understand emotional distress?

Dear

I would like to invite your son/ daughter to take part in a research study. My name is Rebecca Fisher and I am a trainee clinical psychologist conducting a research project for my professional doctorate qualification. Before you decide if you would like your son/daughter to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.. You do not need to decide whether or not your son/daughter participates immediately.

If you have any questions then please feel free to contact and speak to me.. You can phone and speak to me on the following number 0300 555 1156 ex

7208. If I am not in, then you can leave a message and I will return your call to discuss any queries that you may have.

What is the research about?

This research aims to explore:

- How do young people in mental health services describe and understand emotional distress?

Why has your son/daughter been asked to take part?

I am asking all young people who are receiving treatment at █ to take part in this study.

Does my son/ daughter have to take part?

No. It is up to you to decide whether or not your son/daughter takes part. If you decide that they can take part I would like you to sign a consent form. The consent form is a way of making sure you know what you have agreed to on behalf of your son/daughter. If you decide that your son/ daughter can take part they are still free to withdraw at any time and do not have to give a reason. Should they withdraw, the researcher reserves the right to use their anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.

The support and help your son/ daughter receive from their team will not be affected if you or they decide at anytime they do not want to take part.

What will happen next?

If you decide that your son/ daughter can take part, I will be in touch and we will arrange a convenient time and place to meet at █. I would like to meet with your son/ daughter on two occasions.

What do they have to do?

At our first meeting I will answer any questions or concerns your son/ daughter may have. During the second meeting I will ask them about their understanding and experience of emotional distress within the context of their mental health difficulties.

I will also ask your son/ daughter if the second one meeting can be recorded on a digital voice recorder. The purpose of the recording part of our conversation is because the analysis I will use relies on your son/ daughter's exact words that

they use during the interview. I will transcribe what your son/ daughter have said, take out any information that would identify them personally (e.g. names of people), and destroy the recording.

I will show you them recording equipment and demonstrate how it works before starting recording. They will be free to stop the recording at any time during the interview. Importantly there are no right or wrong answers. It is their perspective that I would like to hear.

What is the down side of taking part?

It is possible that our meeting(s) may cover topics that are difficult or distressing for your son/ daughter to talk about. If they feel distressed we can stop the interview. We can also take a break at any time.

Will their taking part in this study be kept confidential?

If you decide that your son/ daughter can take part in the study their clinical team will know that they are taking part. If there is anything in the interviews that they feel would be useful to share with their key worker then I will arrange this for them. If they disclose information that suggests imminent harm to themselves and/or others this information will be, as per █ policy, shared with their clinical team.

In terms of confidentiality the interviews will be transcribed and the information anonymised. Anonymity will be assured by assigning each participant a code. These codes, as well as consent forms will be kept in a locked cabinet. The researcher will transcribe all of the interviews and all identifiable information will be anonymised. On the consent form participants will be asked to give permission for anonymised quotes from their transcripts to be used. Only the researcher, supervisors and examiners will have access to the transcribed material. Data will only be accessed via a password on a computer, and will be erased after five years.

What are the possible benefits of taking part?

Your son/ daughter will not directly benefit from taking part in this research. However, the information I learn from this study will help me plan future research and contribute to the development of new psychological therapies to

help alleviate emotional distress experienced by young people with mental health difficulties.

What will happen to the results of the research study?

I will provide you with a summary of the results of the study. The final results and conclusions of the study may lead to publications in scientific journals. Participants will not be identified in any publication.

Who is organising the research?

The research is being organised by the University of East London.

Who has reviewed the study?

This project has been reviewed and approved by the ethics committee at the University of East London and given managerial approval by the local Research and Development Departments in the North East London Foundation Trust (NELFT). It has also been reviewed and approved by the NRES Committee - Camden and Islington.

If you have any concerns about the conduct of the investigator or any other aspect of this research project, you are encouraged to contact the study's supervisor Dr Katy Berg, School of Psychology, University of East London, Water Lane, London E15 4LZ Tel:020 8223 4409, k.l.berg@uel.ac.uk
or
Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ, Tel: 020 8223 4493, m.finn@uel.ac.uk

Thank you very much for reading this information sheet and for thinking about this study. Please retain this invitation letter for reference.

Yours sincerely

Rebecca Fisher (date)

Appendix 9: Parent/ Guardian Consent Form

Consent form Parent/ guardian Version 2.0   12th May 2014

Study Number:

Participant Identification Number for this project:

<u>CONSENT FORM (Parent/ Guardian)</u>

Title of Project: How do young people in mental health services describe and understand emotional distress?

Name of Researcher**:** Rebecca Fisher, email u1138184@uel.ac.uk, Tel: 0300 555 1156

Please initial box

1. I have the read the information sheet dated 12th May 2014 (version 2.0) relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which my son/ daughter will be involved have been explained to me.

2. I hereby freely and fully consent for my son/ daughter to participate in the study which has been fully explained to me. Having given this consent I understand that they have the right to withdraw from the study at any time without disadvantage to themselves and without being obliged to give any reason. I understand that I also have the right to withdraw them at any time without disadvantages to them.

3. I understand that the involvement of my son/ daughter in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

4. I understand that should my son/ daughter withdraw, the researcher reserves the right to use their anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Parent/ Guardian's Name (BLOCK CAPITALS)   Parent/ Guardian's Signature

……………………………………............   ....

Researcher's Name (BLOCK CAPITALS)   Researcher's Signature

…………………………………   ....

Date: …………………….………

Appendix 10: Participant Assent Form

Participant Assent Form Version 1.0   21st May 2014

Study Number:

Participant Identification Number for this project:

ASSENT FORM

Title of Project: How do young people in mental health services describe and understand emotional distress?

Name of Researcher: Rebecca Fisher, email u1138184@uel.ac.uk, Tel: 0300 555 1156

Please initial box

1. I have the read the information sheet dated 21st May 2014 (version 1.0) relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

2. I hereby freely and fully assent to participate in the study which has been fully explained to me. Having given this assent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

3. I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

4. I understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)   Participant's Signature

…………………………….................   ....

Researcher's Name (BLOCK CAPITALS)   Researcher's Signature

………………………………………   ....

Date: …………………..…….

Appendix 11: Interview schedule

INTERVIEW SCHEDULE

Question 1:

'What I'm trying to understand is how young people understand emotional distress. So if I said to you somebody was experiencing emotional distress, what do you think would be going on for that person?'

Question 2:

'I'm interested in hearing about what you understand about the term emotional distress and what your experiences have been?'

[Follow up probes if necessary]

Examples:

- Can you tell me more about that?

- What was that like for you?

- How did it feel?

- What did you think when distressed?

- How did you behave?

- What did you do?

- What strategies did you use?

- Did the help/ not help

Q4: Is there anything else you would like to add to our conversation today?

[Follow up probes]

Appendix 12: Transcription Conventions (Adapted from Bannister et al. (2011))

(.)	Pause
(2)	Two second pause
[laughter]	Laughter during the interview
/	Marks interruptions and overlapping talk
. ,	Extracts are punctuated to facilitate reading
[Rachel]	Pseudonyms were used for interviewee names
[Name 1]	All other names were anonymised
[Place 1]	All places were anonymised
[Ward 1[	All hospital wards were anonymised
[Service 1]	All hospital services were anonymised
000	Lines are numbered (000 at start of interview)

Appendix 13: Annotated extract of transcript

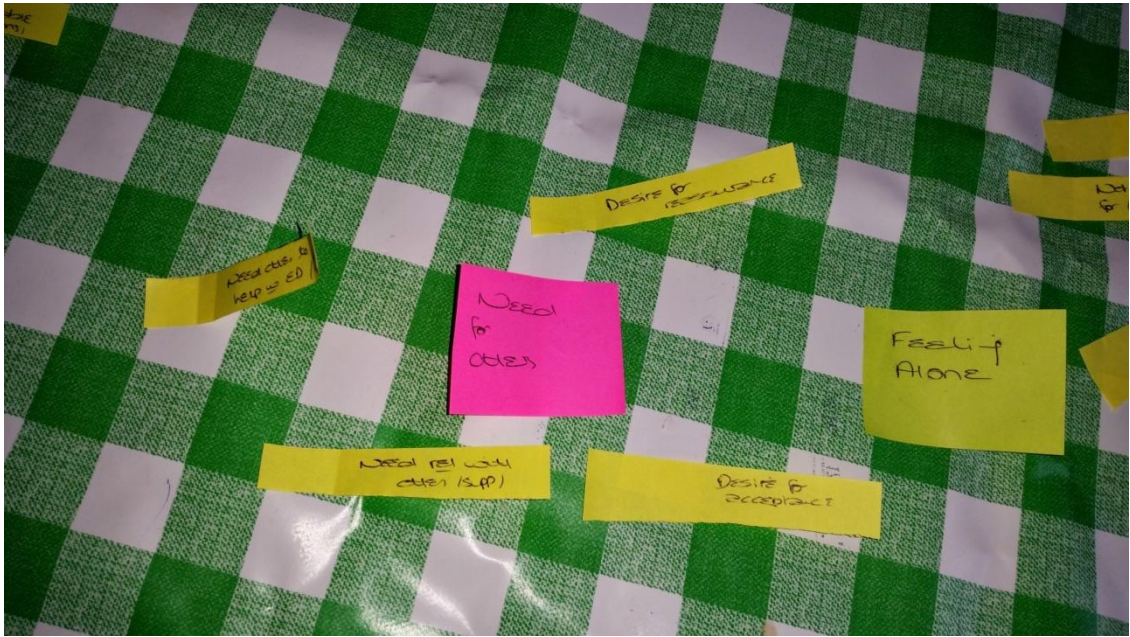**Appendix 14: Examples of initial coding across transcripts**

Code	Excerpt
8. Need to talk about distress	Rachel: 'Erm, I find it really helpful to speak about it and get it out of me (mmm) like get it all of my head (yeah) cos if I leave it in my head and don't speak about it it just plays on my mind' (line 212-214) Emma: '... it's nice to be able to tell someone something and not to be judged, it's just nice to be able to let it out rather than bottle it all up' (line 197-199) Steve: 'Well before when I was upset about what my brother had called me I'd call my mum and told her that I wasn't happy and that I needed some help and she, cos she was out at work, she come home and would sit down and talk to me' (line 161-164)
46. Talking about emotions is difficult	Steve: 'I find it quite hard to descrobe how I am feeling. When I am feeling it at that exact moment I can probably describe it but if it's like to reflect on how I felt about a certain time of day I find it hard' (line 205-208) Claire: It's just quite confusing as well cos like when you're talking about it you can't get your own mind around it even when your're going through it. You're like God, I don't get it' (line 322-324)
71. Dissociation	Anna: 'I get very low and erm I get very scared cos the worse the dissociation gets the more scared I get. (line 37-38) Emma: 'My head just kind of blurs out and I feel really zoned out like spaced out, I don't know what that's called' (line 146-147) Lucy: 'I was just really angry and really out of it (int: what do you mean out of it?) Like I dunno, it's just like it's not me, it's like some other person and it's like I feel drunk and like not in, like not in reality' (line 68-72)
82. Emotions can be blocked	Paul: 'It just, personally, I personally find I can just kind of block out certain kinds of emotions, just like that almost' (line 19-20) Joanne: 'Sleep blocks everything out, it blocks my life out' (line 223)

Appendix 15: Initial Codes Codebook'

1. Distress in the head and body

2. Distress has a context
3. Unable to talk about emotions
4. Unable to express emotions
5. Unable to experience emotions
6. Distress controls your behaviour
7. Dying is the only way to end distress
8. Need to talk about distress
9. Research is not sophisticated
10. Hide distress from others
11. Distress is difficult to quantify
12. Talking is a relief
13. Talking shares burden
14. Talking helps others understand distress
15. Talk helps share the experience
16. Help is needed from others to resolve distress
17. Distress when feel stuck
18. Distress when feel trapped
19. Family unavailable to talk to
20. Family not supportive
21. Family unwilling to help
22. Need to protect others from distress
23. Need to protect myself from distress
24. Being let down by others
25. Different vs normal
26. Not feeling noticed
27. Not feeling cared for
28. Would do things differently in future
29. Not feeling valued by others
30. Not feeling important to others
31. Confusion regarding identity
32. Feeling alone
33. Having to survive
34. Self harm as a coping mechanism
35. Other people are dangerous
36. Hopelessness about distress
37. Blame self for distress
38. Blame self for actions
39. Distress – attack self
40. Distress – attack others
41. Attempted help seeking
42. Don't know how to stop distress
43. Desire for reassurance
44. Need relationships with other people to help
45. Treatment is helpful
46. Talking about emotions are difficult
47. Don't want others knowing about distress
48. Worry what others think about me

49. Expectation of negative judgement from others
50. Others cannot hurt me
51. Distress is controllable
52. Self harm is avoidance of having to talk about distress
53. Self harm protects me from suicide
54. Self harm Is addictive
55. Distress will destroy existence of self
56. Difficulty when thinking
57. Distress is uncontrollable
58. Distress causes me to hear voices
59. Medicalisation of distress
60. Response of professionals
61. Medication
62. Restraint
63. Being sectioned
64. Self harm to feel something
65. Rejection by others
66. Judged by others
67. Dismissal of distress by others
68. Ridiculed by others
69. Not validated by others
70. Unreal feeling
71. Dissociation
72. Emotions are unpredictable
73. Awareness of alternative forms of coping
74. Distress is different for everyone
75. Distress is individual
76. Distress is disguisable to self
77. Distress is disguisable to others
78. Don't wan t others to know I'm struggling
79. Don't know any other way to be
80. Self harm is an expression of distress
81. Not feeling listened to
82. Emotions can be blocked
83. Feeling used by others
84. Feeling understood by others
85. Feeling listened to by others
86. Trying to fit expectations of others
87. Blame others
88. Desire for acceptance
89. Distress is infectious
90. Distress is dangerous
91. Need to change thinking to improve
92. Relationships are risky
93. Scared of distress
94. Self harm is a form of control
95. Self harm is empowerment
96. Cannot function when low in mood
97. Self harm is a connection to body
98. I'm unhelpable
99. Disempowerment

100.   Positive to feel emotions
101.   Trying to keep control
102.   Run away
103.   Escape from distress
104.   Vulnerability
105.   Alien part of self
106.   Self harm is functional
107.   I'm a burden on others
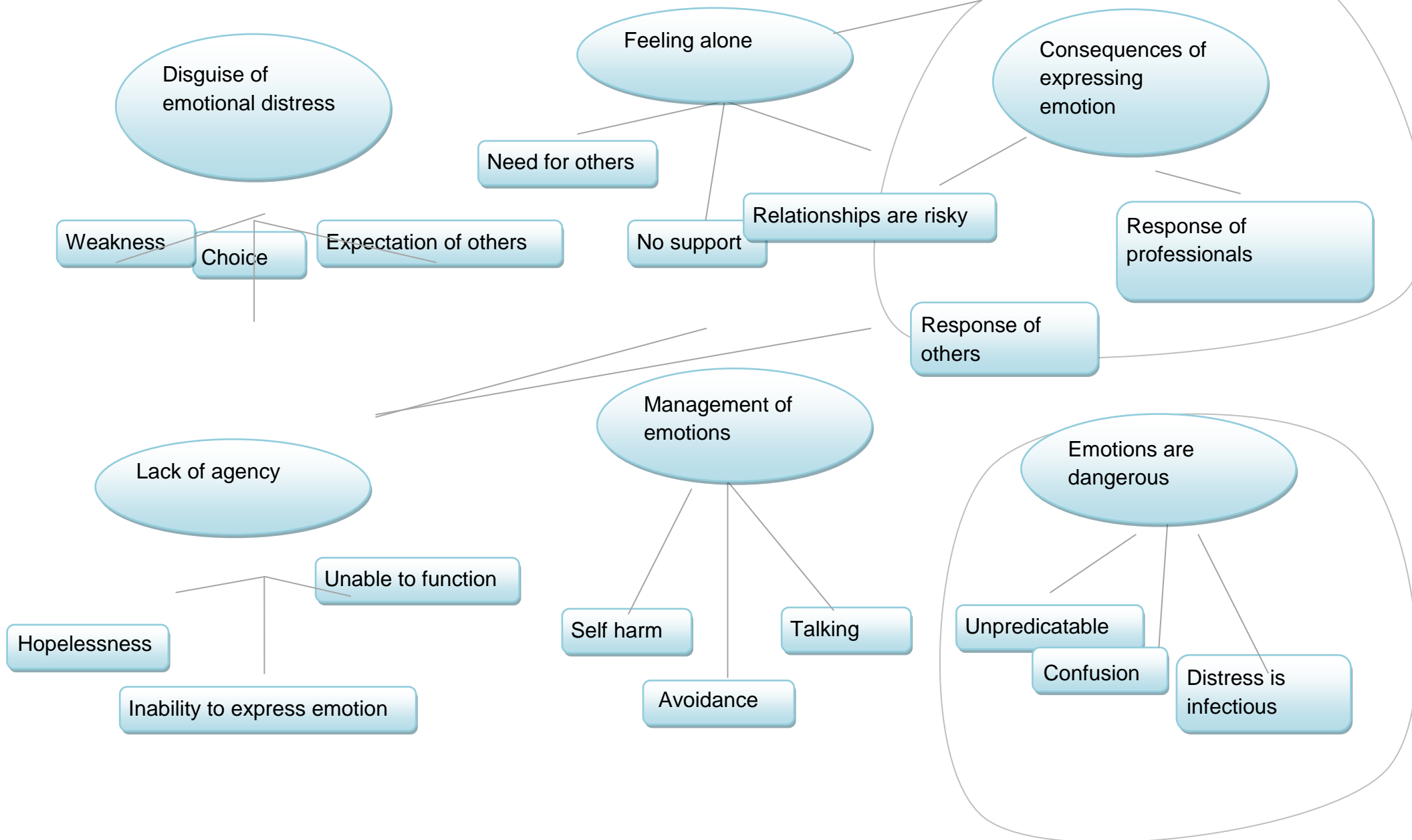108.   Not talking about distress
109.   Self harm is a vicious circle

Appendix 16: Visual representation of codes
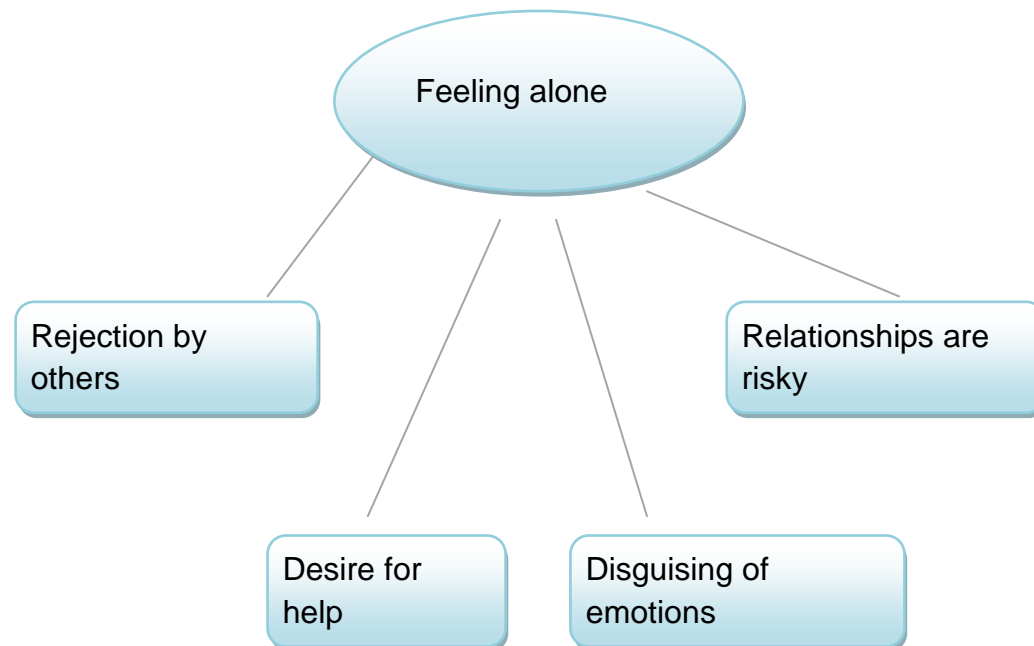
Appendix 17: Initial themes

Disempowerment

Response of others

Disguising emotional

Response of professionals

Consequences of expressing emotion

Self harm

Avoidance

Weakness

Distress controls me

Cannot be helped

Talking is helpful

Helpseeking

Emotions are uncontrollable

Rejection by others

Needing others

Coping mechanisms

Appendix 18: Thematic map 1

Appendix 19:Thematic map 2

Emotions are dangerous

Emotions are uncontrollable

Confusion

Distress is infectious

Management of emotions

Talking

Experience of service

Self harm

Avoidance

Lack of agency

Inability to function

Hopelessness

Medicalisation of distress

Feeling alone

Rejection by others

Relationships are risky

Desire for help

Disguising of emotions

144
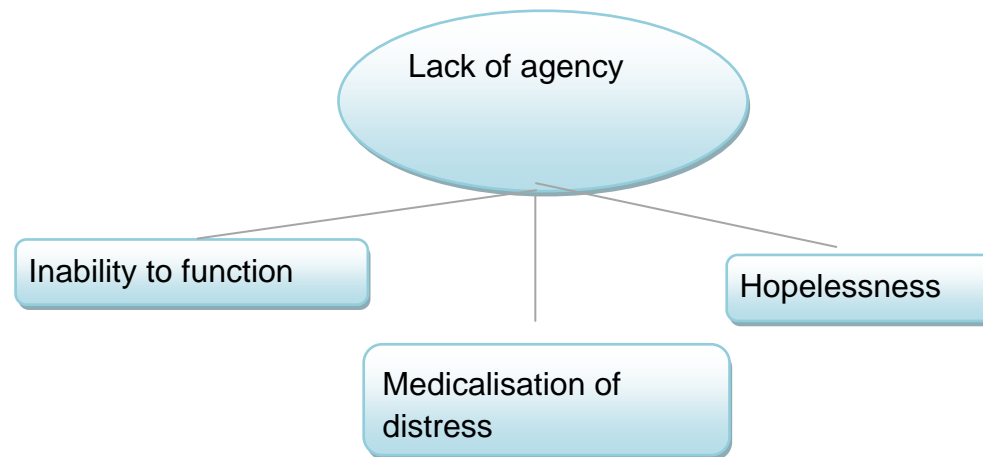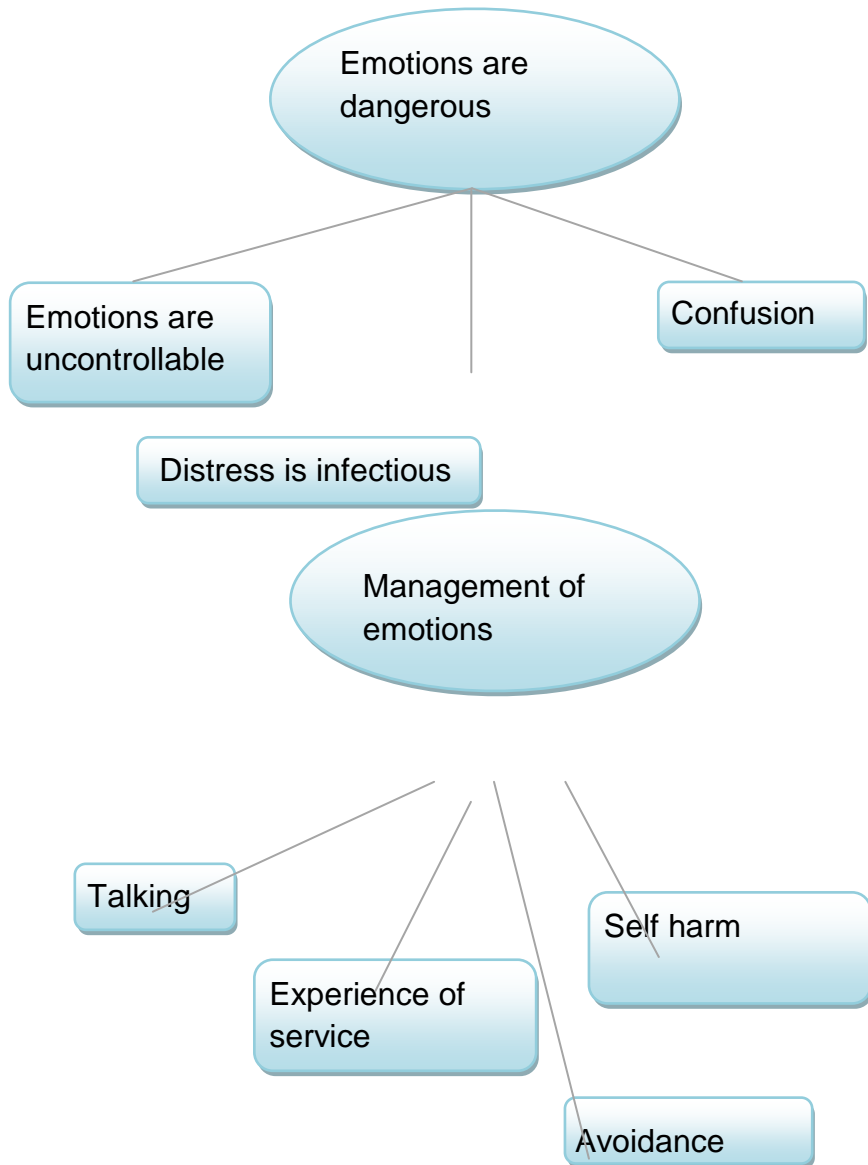
Appendix 20: Final thematic map
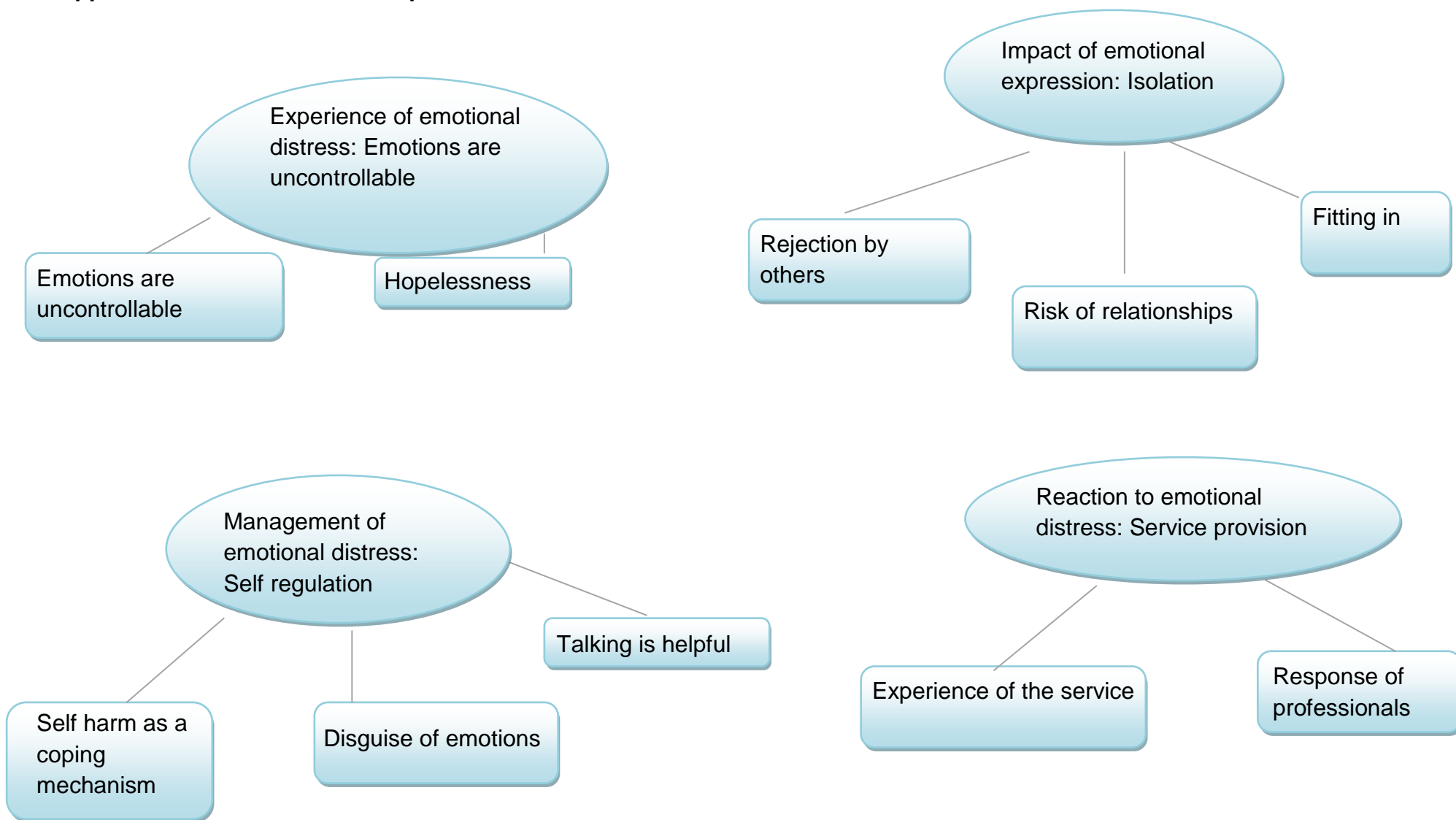
Appendix 21: Naming and defining themes

Theme	Subthemes	Definition	Relevance to research question
Experience of emotional distress: Emotions are uncontrollable		**Young person's experience of having a lack of control when experiencing emotional distress**	**Describes how young people report a lack of agency when both experiencing and expressing their emotional distress to themselves and others. This is also in terms of their own thoughts, feelings and behaviours.**
	Emotions are uncontrollable	Young people do not feel in control of their emotions	This relates to how young people describe their emotions, within the context of their distress, as unpredictable, volatile and potentially dangerous to themselves and others.
	Hopelessness	The belief that the young people do not believe change will occur	Encapsulates the young people's description that neither they nor anyone else can effect change in their lives or experience of distress.
Impact of emotional expression: Isolation		**How young people feel when expressing emotional distress**	**This highlights how young people report their situation to be one of isolation due to interpersonal difficulties and relationships with others as a consequence of expressing distress.**
	Rejection by others	Young people do not receive support when expressing their distress	Across all interviews were reports about how young people have experienced rejection by others that they discuss as because of their emotional distress. Either through talking about it or expressing it in a behavioural way, young people also report exclusion from peer groups.

	Risk of relationships	That young people do not always experience reciprocity in relationships in terms of support	Due to their experiences in relationships when trying to express their distress, young people reported one impact of emotional distress is the development of interpersonal sensitivities. The young people describe ambivalence about the maintenance or development of new relationships.
	Fitting in	That young people feel pressure to conform to the expectations of others.	A sense of not fitting in or conforming to the expectations of peers or society was identified by some young people as a source of and contributing factor to their ongoing distress.
Management of emotional distress: Self regulation		**How young people attempt to regulate their emotional distress**	**This is relevant to how young people try and manage their emotional distress and the mechanisms they use to try and alleviate or disguise it.**
	Self harm as a coping mechanism	Self harm is a functional way for young people to feel in control of their emotions and distress	Young people described self harm as a way to express and alleviate their emotional distress in the moment they are experiencing it. It was also spoken about as a mechanism of empowerment whereby they utilise it as a way to control increasing levels of distress or feel a connection to their body in the context of dissociative states.
	Talking is helpful	Talking is a helpful process to alleviate emotional distress	Young people identified the need and positive impact that talking about their distress has in terms of sharing the burden of their distress. They spoke about how difficult it is to talk through fear of judgement but also in terms of not always having a language to describe their distress.

	Disguising of emotions	Emotional distress can be and needs to be disguised from the self and/ or others.	Young people considered emotions and distress as something that needs to be hidden from others. Due to their experiences of rejection, worry or lived experience about what others think or expect from them, they identify a need to hide their true feelings.
Reaction to emotional distress: Service provision		**The way in which services respond and provide for those experiencing emotional distress**	**Young people discussed a medicalised response to their experiences and expressions of distress yet also considered both their positive and negative experiences within this service.**
	Response of professionals	The response of the professionals not believed to be helpful	That young people report a medicalised response to their expression of distress. Where they report wanting the opportunity to talk they describe being given medication, mental health act law or physical force is used to control their distress.
	Experience of the service	Treatment from the service has had mixed results with some young people feeling benefits and others not so.	Young people acknowledged difficult journeys in trying to manage their distress throughout their treatment with the service. Some described a reduction in their distress and plans for the future. Others talk about the service not helping or not being able to help them with their distress in terms of managing it