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# **Doctoral Thesis:**

Client Experiences of Cognitive Behaviour Therapy (CBT): Factors Influencing Engagement

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# **Statement of Word Count for Thesis Sections**

	Text	References, Tables & Appendices	Total
Thesis Abstract	240	-	240
Literature Review	6,964	8,286	15,250
Empirical Paper	7,885	9,782	17,691
Critical Review	3,446	415	3,861
Ethics	4,501	6,890	11,391
Totals	22,796	25,373	48,433

#### **Abstract**

This thesis constitutes a qualitative exploration of individuals' experiences of cognitive behaviour therapy (CBT) in both physical and mental healthcare settings. The literature review comprises a meta-synthesis of nine papers exploring experiences of CBT, which resulted in the identification of six themes: shared experience allowing reconnection; CBT skills enabling changing relationship with illness; therapist factors central to engagement; therapy as challenging; the importance of being able to talk to someone outside of the family; and therapy as life-changing. The main implication of these findings is the need for greater consideration of the complex nature of social support in the context of chronic illness and the specific challenges and benefits of engagement in CBT in this population. The empirical paper provides a qualitative exploration of the experiences of adults who have dropped out of CBT in a community mental healthcare setting. Thematic analysis resulted in the identification of five themes: the role of therapist factors; limitations of the CBT model; CBT as pathologising; the socio-political context of CBT; and responsibility for engagement and change. This is the first qualitative exploration of CBT drop-out across diagnostic groups and, as such, this study contributes an important insight into the challenges associated with engagement in CBT and the influence of socio-political context. Finally, the strengths, limitations and challenges of the research process are discussed in the critical appraisal, with particular reference to the broader theme of occupying the position of both clinician and researcher.

# **Declaration**

This thesis represents work undertaken for the Doctorate in Clinical Psychology at Lancaster			
University, Division of Health Research, from May 2014 to May 2015.			
The work presented is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.			
Name: Kay Brewster			
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Date:			

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I would firstly like to thank the 11 participants who made this research possible, by giving up valuable time to share their experiences. I would also like to recognise the support of the various services that assisted with recruitment.

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# Section One: Literature Review

# User Experiences of Cognitive Behaviour Therapy (CBT) for a Chronic Physical Health

Condition: A Qualitative Meta-Synthesis

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# User experiences of cognitive behaviour therapy (CBT) for a chronic physical health condition: a qualitative meta-synthesis

The role of psychosocial factors in promoting healthy adjustment to a chronic physical health condition is well recognised. There has thus been a growth in the provision of psychotherapy in this context, particularly cognitive behaviour therapy (CBT). There is strong empirical support for the efficacy of CBT and an increasing amount of qualitative research also supports CBT as an appropriate model. The aim of this meta-synthesis is to bring together relevant qualitative studies in this area, in order to create a more comprehensive understanding of the experiences of individuals with a chronic physical health condition who engage in CBT. Six electronic databases were searched, using predefined search terms, inclusion and exclusion criteria, and a quality appraisal framework. Following an additional hand-search of the references and citations of key articles, nine international studies were identified for inclusion in the meta-synthesis. Using the meta-ethnographic process suggested by Noblit and Hare, six themes were identified: shared experience allowing reconnection; CBT skills enabling changing relationship with illness; therapist factors central to engagement; therapy as challenging; the importance of being able to talk to someone outside of the family; and therapy as life-changing. These findings add to the existing literature by highlighting the complex nature of perceived social support in the context of chronic illness and the specific challenges experienced in relation to CBT in this population. Further research is indicated to explore the experiences of individuals who drop out of, or do not benefit from CBT for a chronic physical health condition.

**Keywords:** meta-synthesis; CBT; chronic illness; qualitative; psychological adjustment

Chronic illnesses have been defined by the World Health Organization (WHO) as "health problems that require ongoing management over a period of years or decades" (WHO, 2002, p. 11). This definition is intentionally broad, in recognition of the need to incorporate not just diseases (such as cancer, cardiovascular disease and diabetes), but also impairments (such as amputations, joint disorders and blindness), neurological conditions (such as multiple sclerosis and chronic pain) and persistent mental health difficulties. There is additional complexity in that individuals can experience co-morbidity of chronic physical and mental health difficulties such as depression and anxiety; for example recent research has suggested that there is a bi-directional relationship between depression and type 2 diabetes (Renn, Feliciano & Segal, 2011). This co-occurrence of chronic physical and mental health difficulties is also highlighted by the National Institute for Clinical Excellence (NICE) in their clinical guideline for the treatment of depression in adults with a chronic physical health problem (NICE, 2009). Research has shown that key factors influencing individual experience of chronic illness are self-management, social support and psychological adjustment.

# Self-management

Many chronic illnesses involve a significant level of self-management, for example adherence to a medication regime, an increased level of physical activity and dietary control, in addition to specific activities relating to particular illnesses. It is recognised (Newman, Steed and Mulligan, 2004) that self-management goes beyond basic adherence, to incorporate the psychological and social management of living with a chronic illness.

# Social support

The systemic factors influencing adjustment to, and management of, a chronic condition are well recognised in existing research. These are outlined by Cukor, Cohen, Peterson and Kimmel (2007) in their paper on the psychosocial aspects of chronic disease, in the context of

end-stage kidney failure. The authors describe the complex interaction between the individual and their partner, family, social network, treatment programme and culture and highlight the necessary adjustment to a changing identity and life role.

In a meta-analysis of 122 studies investigating the relationship between social support and medical adherence in the context of chronic illness, DiMatteo (2004) found that there was a strong positive correlation between practical and emotional social support and adherence. Family cohesiveness was also found to predict adherence, whereas conflictual, distant family relationships predicted non-adherence. Living with someone else and being married were also factors shown to have a positive effect on adherence. The latter circumstances were classified as structural social support and were found to have less of an effect in comparison to practical, emotional and familial support factors.

Similarly, in a review of the literature on the relationship between social support and self-management of chronic physical health conditions, Gallant (2003) found that there was a moderate positive relationship between social support (particularly disease- or regimenspecific) and chronic illness self-management, particularly for individuals with diabetes. The potentially negative effect of social support was also highlighted, for example the additional pressure experienced when attempting to meet family commitments in addition to fulfilling the illness regime and the experience of negative or unhelpful comments by others in an individual's support network.

Chronic physical health conditions are often not visible (such as chronic pain or chronic fatigue syndrome) and for some, there is a relative lack of a diagnostic, clinical test in comparison to illnesses such as diabetes or cancer. These conditions can thus be perceived as dubious by friends and family members, which can lead to a lack of social support (Duff, 2003).

# Psychological adjustment

Research has indicated that several factors are important for promoting healthy psychological adjustment to a chronic illness: remaining as active as possible, acknowledging and expressing emotion in an empowering way, engaging in self-management of the illness and focussing on potential positive outcomes of the illness (de Ridder, Geenen, Kuijer, & van Middendorp, 2008).

The most commonly applied model for understanding psychological adjustment in the context of illness is the self-regulatory model (e.g. Brownlee, Leventhal & Leventhal, 2000), which suggests that individuals actively construct illness representations that contain information about five aspects of the illness: identity, cause, consequences, cure and control. These representations can be either abstract or concrete and can operate at both the cognitive and affective level. There is evidence, for example from Jopson and Moss-Morris' (2003) study on psychological adjustment to multiple sclerosis, that an individual's illness representations can significantly predict levels of social dysfunction, fatigue, anxiety, depression and self-esteem.

Recent research (Clark, Gong & Kaciroti, 2014) has indicated that the three self-regulatory processes of observation, judgement and reaction are central to an individual's ability to control chronic illness. According to this model, an individual's ability to make judgements about their health, based on actual observations rather than fear, habit or tradition, leads to increased confidence, self-efficacy and use of disease-management strategies. Clark et al suggest that self-efficacy is influenced by external factors such as technical advice, material resources and role models, all of which are often provided by clinicians, in conjunction with existing social support networks.

# Psychological approaches to chronic illness

There is widespread acknowledgement of the role of psychotherapy in supporting individuals to adjust to and manage a chronic health condition, and the predominant recommended model (e.g. NICE, 2009) for this is CBT. The importance of considering an individual's broader psycho-social context in the treatment of a chronic physical health condition has also been highlighted (Turner & Kelly, 2000), in relation to both the initial onset of a chronic health condition and in maintaining difficulties post-diagnosis (Schneiderman, Antoni, Saab & Ironson, 2001).

CBT in the context of physical illness involves supporting the individual to adopt a realistic and optimistic attitude towards their illness and to develop adaptive coping strategies to alleviate symptoms. Structured CBT programmes thus typically include a psychoeducational component, goal setting and pacing, relaxation strategies, cognitive strategies, communication skills and relapse prevention and risk management (Sharpe & Curran, 2006). The co-morbidity of physical and mental health difficulties has been highlighted as an additional complexity when considering psychosocial intervention for chronic illness. In their meta-analysis of psychosocial interventions that target both physical and mental health in individuals with diabetes, Harkness et al. (2010) found that none of the 73 studies they included provided evidence for a psychosocial intervention that targeted both of these aspects. CBT was one of the most commonly used interventions; however it was reported as either a lifestyle-based intervention, targeting difficulties specific to the diabetes or a psychological intervention, aimed at reducing associated mental health difficulties such as depression. Harkness et al. highlighted the important challenge of seeking to provide an integrated bio-psychosocial intervention that targets all aspects of a chronic illness such as diabetes at an individual level.

Several quantitative studies, based predominantly on randomised controlled trials, have supported the efficacy of CBT for chronic physical health conditions. In a meta-analysis of psychological interventions for chronic low back pain, based on data from 22 randomised controlled trials, Hoffman, Papas, Chatkoff and Kerns (2007) found that CBT proved superior to waiting list control groups in reducing post-treatment pain intensity. Self-regulatory treatments, such as biofeedback and relaxation programmes, were found to be marginally more effective than CBT in reducing post-treatment depression. They also found that multidisciplinary approaches to chronic pain management that included a psychological component were the strongest predictors of behavioural outcomes, such as an individual's ability to return to work.

A meta-analysis of 13 studies investigating the efficacy of CBT for chronic fatigue syndrome (Malouff, Thorsteinsson, Rooke, Bhullar & Schutte, 2008) found an overall medium effect size for CBT, delivered in various formats, in reducing fatigue. Of the five studies that reported follow-up data, only 50 percent of participants experienced a reduction in fatigue to below the level of diagnostic classification, suggesting that CBT alone may not always be sufficient in addressing symptoms of chronic fatigue.

In a meta-analysis of 20 studies exploring the effectiveness of CBT in reducing distress and pain associated with breast cancer, Tatrow and Montgomery (2006) found that between 62-69 percent of participants in the CBT experimental groups did better than those in the control groups as measured by a reduction in distress and pain. There was greater support for individual CBT approaches than for group-based programmes in reducing distress; however no significant difference was found for pain reduction between models of CBT delivery.

Several qualitative studies have also been published, which have sought to explore individuals' experiences of CBT in the context of a chronic physical illness. Five of these

studies were identified during the literature search and, although excluded as they did not meet the inclusion/exclusion criteria for this meta-synthesis, each provided qualitative support for the benefit of CBT for individuals with a chronic physical health condition.

As part of a mixed-method study exploring suffering and alleviation associated with a CBT-based chronic pain management programme, Dysvik, Kvaloy and Furnes (2013) analysed the written reports of 34 participants. They found that 83 percent of the participants expressed satisfaction with the programme, immediately post-intervention and at six-month follow-up. Two initial themes were identified, associated with an increased understanding of the participant's own efforts, needs and wishes, and the value of support from other group members. At follow-up, three additional themes were developed: knowledge of the healthy components of the change process, awareness of emotional, cognitive and behavioural changes and movements towards a better life.

Taylor and Ingleton (2003) explored service user experiences of a mixed intervention involving hypnotherapy and CBT for support with emotional distress associated with cancer. Based on interviews with eight participants, they found that four common themes emerged, based on the perceived importance of accessibility and flexibility of the intervention and the experience of long-term benefits associated with participation.

Edelman, Lemon and Kidman (2005) conducted a qualitative evaluation of a group CBT intervention for breast cancer. Based on 25 telephone interviews with participants, they found that reasons for joining the group were largely related to the therapeutic modality, in providing psycho-education and skills development rather than just a support forum. Many of the participants reflected on the positive benefit conferred by the group process and normalisation by others of their own experience. Additionally, participants commented positively on the structure and content of the CBT programme in aiding their development of specific coping skills and enabling change at a cognitive and emotional level.

Tshabalala and Visser (2011) conducted a qualitative evaluation of a CBT model to assist women to deal with HIV and associated stigma. Participants reflected on the positive changes they had experienced in their thought patterns and behaviour around the HIV, and the associated empowerment this shift in self-perception had given them. Ultimately, this then led to acceptance of their HIV status and greater disclosure to others. Several specific CBT techniques were found to be useful in achieving this change.

The fifth paper explored families' perspectives of CBT versus psycho-education for young people with chronic fatigue syndrome (Dennison, Stanbrook, Moss-Morris, Yardley & Chalder, 2010). The authors interviewed 16 young people and their parents and found that generally, the behavioural aspects of the CBT model were perceived to be more helpful than the cognitive aspects and that all participants valued the opportunity to talk and be supported and have their difficulties recognised and validated.

There is thus a large amount of literature, both quantitative and qualitative, that supports the use of CBT for chronic physical health conditions. There currently exists no meta-synthesis of the qualitative studies in this area. With the growing recognition of the role for clinical psychologists in delivering health psychology interventions, the current meta-synthesis is both relevant and timely.

# Methodology

The focus of this meta-synthesis is on the experiences of individuals who engage in cognitive behavioural therapy for support in living with a chronic physical illness. The meta-synthesis was conducted in adherence with the guidelines outlined by Noblit and Hare (1988), who proposed "an inductive and interpretive form of knowledge synthesis" (p.16) in which "interpretations and translations," rather than "analyses and generalisations" are constructed (pp.11 & 23). Noblit and Hare highlight the nature of qualitative meta-syntheses as interpretation (by the analyst) of interpretations, and stress that there is "no value in a

synthesis that is not of interest to the author" (p.27). It is thus important to acknowledge that the author's interest in this meta-synthesis research question is influenced by their experience of delivering CBT in both mental health and physical health psychology services.

# Searching for studies

A five-phase approach was adopted in searching the literature (see Figure 1). In phase one, relevant papers were identified by searching the following key databases, identified within the specialised subject library guide for clinical psychology and chosen for their relevance to the topic area: 'Academic Search Complete' (searchable years 1887-2014), 'CINAHL' (searchable years 1981-2014), 'Medline' (searchable years 1809-2014), 'PsychINFO' (searchable years 1600s - 2014) 'AMED' (searchable years 1985 - 2014) and 'Embase' (searchable years 1947 - 2014). Additional criteria selected were "peer-reviewed," "primary source document," "journal article," "English language," "fully published," "exclude dissertations" and "qualitative study." The full-text search terms used were ["client\*" OR "user\*" OR "patient\*" OR "participant\*" OR "individual\*"] AND ["experience\*" OR "view\*" OR "percept\*" OR "perspect\*" OR "opinion\*" OR "attitude\*" OR "belief\*" OR "feel\*" OR "understand\*" OR "know\*" AND ["CBT" OR "cbt" OR "cognitive behaviour therapy" OR "cognitive behaviour therapy" OR "cognitive behavioral therapy" OR "cognitive behavioural therapy"] AND ["qualitative" OR "meta-synthesis"]. Further limits relating to specific chronic physical illness were not included at this stage, due to the breadth of applicable terms and so as not to accidentally overlook relevant papers. No limits were set on the date, source or gender within publications. This initial search, conducted on 5<sup>th</sup> November, 2014, yielded 172 papers across the six databases (once duplicates were removed). At this stage, 126 papers were excluded based on the inclusion and exclusion criteria, as detailed below (non-italicised):

#### Inclusion criteria

- (1) Papers which were published in a peer-reviewed journal, in order to represent appropriate quality and also to reflect a lack of funding to access dissertations, theses and books.
- (2) Papers which were published in English, due to a lack of access to translation resources.
- (3) Papers which used qualitative methodology, and to reflect first person accounts either from individual participants or focus groups. Papers using any type of qualitative methodology that permitted extraction of themed data were included. Where a paper had used a mixed methodology, qualitative data was extracted where available.
- (4) Papers in which participants had experienced either group or individual CBT, as research has shown that both modalities give equivalent outcomes (Holmes & Kivlighan Jr, 2000)
- (5) Papers which focussed on adult experiences of CBT in the context of any chronic physical health condition

#### Exclusion criteria

- (1) Papers in which no qualitative analysis was reported.
- (2) Papers which focussed on research into CBT delivered via computer or self-guided CBT.
- (3) Papers which focussed on the experiences of individuals who have dropped out of CBT. Where a paper included experiences of both CBT completers and those who had dropped out prematurely, attempts were made to extract the data relating to completers. This limitation was placed in recognition of the existing broad parameters for inclusion in this meta-synthesis, in order that some homogeneity was achieved.

- (4) Papers which focussed on the experiences of families or carers, or individuals under the age of 18.
- (5) Papers which focussed on the experiences of individuals accessing CBT primarily in the context of a mental health difficulty, with no associated chronic physical health condition.
- (6) Papers which focussed on the experiences of individuals with transient (i.e. non-chronic) physical health conditions.

During the second phase of searching the literature, the full-text of the 46 papers was reviewed and three additions were made to the inclusion and exclusion criteria (italicised above) in order to refine the search based on a chronic physical health context. Based on this refinement, a further 39 papers were excluded. The third phase involved searching the Cochrane online library and a hand-search of the references and citations of key articles, during which a further two papers were identified. Nine papers were thus included in the final meta-synthesis.

[Figure 1 near here]

# Characteristics of the selected studies

The nine papers included in the meta-synthesis are summarised in Table 1. All were published between 1998 and 2015. Six of the papers were based on European populations (two in Norway and four in England). Two papers were based on populations in America and one in Australia. Sample sizes ranged from 7-38 and included both genders and a combined age range across the studies of 18-77. Four of the studies focussed on the experiences of individuals with chronic pain; three studies focussed on cancer; one study on multiple sclerosis and one study on rheumatoid arthritis. The format of CBT experienced across the studies was either group or individual (with or without a telephone-based component), with a suitably qualified therapist, and the duration of CBT accessed ranged

from 6 to 12 sessions. All but one of the studies collected data via individual interviews, the other used focus group interviews. All nine studies used a form of thematic data analysis.

Only two studies reported details of the ethnicity of participants.

[Table 1 near here]

# Quality appraisal of the selected studies

It has been suggested that with qualitative meta-syntheses, studies "should not be excluded for reasons of quality, because ... there are wide variations in conceptions of the good, and in quality criteria" (Sandelowski, Docherty, & Emden, 1997, p.368). However, it was felt that in order to adopt a truly comparative approach, as suggested by Noblit and Hare (1988), it was important to consider the relative reliability and trustworthiness of studies selected for the final metasynthesis. As such, each of the nine studies was assessed using the Critical Appraisal Skills Programme (CASP) checklist (Public Health Resource Unit, 2006). This tool enables an assessment of ten areas applicable to qualitative research; two of which are screening questions for the clarity of the study aim and appropriateness of a qualitative approach and the remaining eight relate to aspects of the methodology, design and findings (a list of the CASP checklist questions can be found in appendix 1-1). For the current metasynthesis, each of the nine studies was given a score out of three in each of the ten areas (1 = no; 2 = can't tell; 3 = yes), then a total score out of 30, to give an indication of relative and overall strengths and weaknesses. All studies met the screening criteria in demonstrating a clear statement of the aims of the research and in using qualitative methodology appropriately. The individual and total scores can be found in Table 2; the total scores of the nine papers fell between 25 and 29 (mean = 27.11). Four of the papers (selected based on a representative sample of total scores) were peer-audited by a colleague unconnected to the metasynthesis, as a result of which two of the papers were discussed and their total scores amended by one point. The areas that emerged as weakest across the studies were researcher

reflexivity, consideration of ethical procedures and the value of the research. This may partially reflect practical constraints relating to the maximum word count of published manuscripts and also the inherently small sample sizes recruited in qualitative studies. It is important to note that the CASP checklist emphasises the quality of information portrayed within the written reports of studies, rather than the quality of the research itself, thus scores obtained should be considered only in this context.

[Table 2 near here]

# Analysis and synthesis of the selected studies

Following the approach described by Noblit and Hare (1988), the studies were initially read, then the key relationships considered. At this stage, an initial list of the key quotes and themes from each study was collated (see appendix 1-2 for an example of this process). Noblit and Hare describe relationships between studies as either "reciprocal" (p.38), based on similarities across themes and concepts, or "refutational" (p.47), by which competing explanations are suggested across themes or concepts. Based on the initial collation of themes, the nine studies in this meta-synthesis were found to have a reciprocal relationship. The next stage involved the synthesis or 'translation' of key metaphors or concepts within, then across, each of the studies (see appendix 1-3 for an example of theme development). This translation constituted the first level of synthesis, following which the translations were compared to determine whether some of the themes encompassed those of other accounts; a process of "analysing types of competing interpretations and translating them into each other" (p.28). The resulting theme areas that emerged across the nine studies were then grouped according to the concepts they represented.

# **Findings**

Six shared concepts were identified within the studies (see Figure 2):

- (1) Shared experience allowing reconnection
- (2) CBT skills enabling changing relationship with illness
- (3) Therapist factors central to engagement
- (4) Therapy as challenging
- (5) The importance of being able to talk to someone outside of the family
- (6) Therapy as life-changing.

[Figure 2 near here]

Figure two presents the six themes within a longitudinal model, in which the overarching theme providing the context for change to occur, was participants' perception of a shared experience through engagement in CBT, allowing for reconnection to a pre-illness life and identity. The key processes influencing in-session change as a result of CBT were: experiences in relation to therapist factors, techniques and aspects of the CBT model, and challenges associated with the model. Where positive change occurred, it was experienced as life-changing and as an enduring consequence of engagement in CBT. This lasting change process was further supported by the specific experience of being able to talk to someone outside the family (therapist or other group members). A detailed summary of each of the six themes is as follows.

"So I'm not the only one" (MacCormack et al., p.56)

# Theme 1: Shared experience allowing reconnection

The key concept connecting all others across the studies was the sense by participants that engagement in therapy permitted a sharing of experience and reconnection to life beyond illness. Although participants in over half of the studies had received CBT in group format, this theme was also shared in the accounts of participants who had engaged in individual therapy. For those who had experienced group CBT, participants reflected on the integral

process of "bonding together" (Bottomley, p. 27) as a group, which had permitted the sharing of common difficulties whilst also respecting individual experiences:

When I described how I felt, the other members in the group understood me. I received a lot of encouragement and support. It felt good to open up. There was a nice feeling of community in the group. It was good to share my own thoughts with the others. The leaders woke me up, and they helped me to be able to see life in different ways. (Furnes et al., p.5)

Participants identified with the "shared language" (Haraldseid et al., p.16) within the group, which was described by one participant as feeling "like a big family" (Day et al., p.946). Individuals were brought together in the group community, which reduced the sense of isolation that participants had previously experienced as a result of their physical condition: "You realise that a lot of other people have the same thoughts that you have. And before that I didn't know that other people felt the same way about things as I did …" (Dennison et al., p.984).

Participants that had received individual, rather than group CBT, described a similar process by which sharing experiences via their therapist enabled a virtual sense of community with people undergoing similar difficulties, as "it helped to talk to somebody who talks to people in this situation" (MacCormack et al., p.56). The role of the therapist in normalising individual experiences in the context of physical illness was strongly felt by participants across the studies: "She was accepting and made me see that a lot of it was very understandable ... normal ... not odd" (Omylinska et al., p.89).

Several studies have sought to explore the relative effectiveness of group versus individual psycho-education or psychotherapy in various settings. Rickheim, Flader, Weaver and Kendall (2002) conducted a study on group versus individual education programmes for management of type 2 diabetes. They found that both formats were equally effective across a

range of outcomes; however the group-based format led to a slightly greater improvement in glycaemic control. Similarly, a study comparing group versus individual CBT for chronic pain management in an outpatient setting (Turner-Stokes et al., 2003) found little difference in the effectiveness of the two methods at any of the major time points immediately post-intervention, after two months and at one year follow-up. Conversely, some research has indicated that the nature of therapy delivery may influence some treatment outcomes, for example Tatrow and Montgomery's (2006) finding that individual therapy was more effective in reducing distress and pain in individuals with breast cancer.

In their exploration of factors influencing change processes in group versus individual psychotherapy, Holmes & Kivlighan Jr (2000) highlight that, generally, previous research findings have shown equivalence in treatment outcome between the two modes of delivery. They then suggest different mechanisms for change in each modality. In group settings, they propose that outcome achievement is primarily influenced by relational factors, such as feeling supported and encouraged, and ability to compare and share with others. In individual settings, outcomes are influenced largely by development of personal insight and understanding and making progress towards problem-solving techniques.

Interestingly participants in the current meta-synthesis appeared to experience the relational component of therapy as particularly beneficial, irrespective of whether they received group or individual CBT. Participants in all studies also reported benefits associated with specific techniques learned through the CBT.

"It's not gonna rule my life" (Dures et al., p.575)

# Theme 2: CBT skills enabling changing relationship with illness

In all nine studies, a key theme was the perceived value of specific CBT techniques in enabling participants to relate differently to their illness. The role of CBT in increasing awareness and understanding of psychological factors was emphasised, as "until you

understand it you don't know how to stop it, do you" (MacCormack et al., p.499). This increased awareness helped some participants to recognise and re-evaluate negative self-judgements, for example "I don't feel guilty because I don't call myself lazy anymore" (Dures et al., p.499). For one participant, this newfound insight into the link between physical and psychological processes was the most influential aspect of therapy:

I believe that through controlling your feelings and your thought process, you could probably have an influence on your pain level, and it's something I'm still not very good at, but that's probably one of the biggest things I've learned. (Matthias et al., p.574)

The subsequent development of coping skills in relation to specific symptom reduction techniques was described by many participants. These skills included pacing of activity, positive self statements, relaxation strategies, self-monitoring and negative thought challenge. The use of therapeutic writing was also experienced as helpful by participants in several studies, as "after you had written it down, you gained a new focus, you shared with others, and you got advice and guidance" (Haraldseid et al., p.16)

This concept then developed for participants in all studies beyond the application of skills to a broader evaluation of their relationship with the illness. Participants described a process of learning to accept the limitations of their physical health condition and take responsibility (MacCormack et al) for finding a way to move forward with their lives. With this re-evaluation came an increase in confidence and empowerment: "... I have become more aware of my own potential to influence things. I think I have become more conscious about being active, more reflective, and make better choices based on new goals" (Day et al., p.5).

The recent model of self-regulation for chronic illness proposed by Clark, Gong and Kaciroti (2014) highlights the central processes of observation, judgement and reaction in enabling self-regulation of a chronic illness. CBT for chronic physical health conditions

involves assisting the individual to identify their negative, often distorted, thoughts and beliefs that are causing distress and affecting motivation and self-care. The individual is then supported to find a more balanced, positive perspective on the illness and practice this new perspective (Peyrot & Rubin, 2007). The CBT model thus fits well with Clark et al's self-regulation model for chronic illness.

There is a wide body of literature that has sought to explore the relative influence of common factors, such as therapist qualities and allegiance and the therapeutic alliance, versus model-specific factors in psychotherapy (e.g. Messer & Wampold, 2002). In a meta-analysis of 17 meta-analyses on this phenomenon, Luborsky et al (2002) found mainly non-significant or small effect sizes for comparisons of different psychotherapy treatments, indicating that common factors are more influential than model-specific factors in predicting treatment outcome. The current meta-synthesis, however, supports the influence of both model-specific techniques and common, therapist factors in participants' experiences of CBT for a chronic physical health condition.

"They helped you come out of yourself" (Bottomley, p.27)

# Theme 3: Therapist factors central to engagement

In six of the studies, the essential role of the therapeutic alliance in enabling participants to engage in CBT and develop the skills was highlighted. Personal and professional qualities of the therapist were deemed as important; such as warmth, honesty, genuineness, patience and the ability to be both upfront and caring at the same time (MacCormack et al.). These qualities enabled the development of a trusting relationship, which consequently enabled the therapist to "bring things out" (Day et al., p.948). In one study (Dennison et al.), the importance of therapist knowledge of the physical illness was emphasised; participants were better able to trust when they trusted the expertise of their therapist. The encouragement and non-judgemental approach of the therapist also enabled participants to divulge difficult

aspects of their emotional experience: "I could open up, not be ashamed of my feelings, and you know she really cared" (MacCormack et al., p.56). The role of the therapist as facilitator and guide was also acknowledged in one study, by several participants: "We couldn't have got through it on our own just talking about it on our own ... needed those guidelines ... we may have pulled one another down in some cases" (Dures et al., p.498).

Lambert and Barley (2001) provided a summary based on existing research of the factors found to influence psychotherapy outcomes and highlighted the central role of common factors such as warmth, empathy and the therapeutic alliance in effecting change at the individual level. This relative influence of therapist factors has been shown to be prominent in relation to the therapeutic alliance in individual therapy and cohesion as an integral component of group therapy (Norcross & Wampold, 2011). This finding is supported by the current meta-synthesis, as participants who had received group and individual CBT reflected on the importance of therapist factors in supporting their engagement and effective change processes.

An additional consideration in relation to the therapeutic relationship is the role of individual decision-making and involvement with other healthcare professionals in the context of chronic illness. Psychotherapy such as CBT occurs in the context of an existing relationship between the individual and a wider medical team, with which an existing alliance will have been formed. It has been suggested (Montori, Gafni & Charles, 2006) that there is a need for partnership between the individual and their medical clinician in making difficult treatment choices and also a need for ongoing partnership between the clinical team and the individual. Thus, therapy such as CBT does not occur in isolation and individuals may have pre-existing expectations of CBT based on their existing relationships with other healthcare professionals.

# "At first I thought it was all mumbo jumbo" (Bottomley, p.27)

# Theme 4: Therapy as challenging

Challenges to effective engagement in CBT were described by participants in seven of the nine studies. The CBT model was experienced by some as difficult to understand at first, and several participants reflected on the need to fully engage and participate over time, in order to effect change: "... he would be asking us questions ... and my brain was totally blank because then I kept thinking, 'Try to understand what he's talking about' you know? But it does fall into place" (Dures et al., p.498).

Barriers to engagement directly relating to participants' physical health status were also highlighted. In two studies (MacCormack et al. & Dennison et al.), the nature of many chronic illnesses as relapse-remitting was identified as influential in affecting individuals' ability to commit to regular attendance and skills practise. For others, specific symptoms associated with their chronic physical health condition had a detrimental effect on their ability to engage: "It's quite a long time for people with arthritis to sit in one position on one chair too in some of these sessions" (Dures et al., p.498). This experience by some participants highlights an additional practical consideration of accessibility when setting up psychotherapy services for individuals with chronic physical health difficulties.

The double-edged nature of therapy as useful in helping with current problems and stressful life events whilst also perceived as a burden in itself was highlighted (Dennison et al.), and also the difficulty in discussing distressing topics such as death and cancer (Bottomley). The strength of therapeutic alliance and flexibility of therapist approach in responding to participants' needs, and not rigidly following a manual, was described as important in participants' ability to persevere with CBT, despite these challenges.

Research has shown that not only is therapy challenging, it can also be experienced as harmful by some individuals. Barlow (2010) summarised the potential harmful effects as

relating to either a decrease in function as a result of therapy or a mismatch of expectation and experience associated with therapy, causing a loss of hope. Although none of the participants in the current meta-synthesis experienced CBT as harmful, the context of chronic illness presents an additional complexity in relation to the implicit discussion of highly distressing and emotive experiences and the importance of setting realistic expectations of achievable change.

"I was able to tell her things I probably wouldn't tell other people" (Dennison et al., p.979)

Theme 5: The importance of being able to talk to someone outside of the family

Five of the studies highlighted the perceived usefulness by participants of being able to share their experiences in a protected space outside of their family lives. Participants described the importance of talking to someone "objective" and not "emotionally involved" (Dennison et al., p.979). Therapists were perceived as being able to cope with hearing difficult experiences; participants were thus less responsible for the potential impact of their feelings and were able to share more deeply without fear of burdening:

... It was nice to have someone outside the family ... and not hold back about anything. To be able to actually express how I felt, how everybody in the family felt about it and not have them say 'oh, do you really feel like that.' (MacCormack et al., p.56)

For some participants, talking to the therapist permitted greater disclosure and acknowledgement of difficulties than with family members, as the therapist was experienced as non-judgemental: "(my family) might have said 'you are here and that's the important thing.' I am here but it is not sorted ... but I couldn't say that because it sounded selfish and could say it to the psychologist" (Omylinska et al., p.88).

One study highlighted the positive benefit of improved communication with family member as a secondary gain of engagement in CBT: "I think my friends and family, I would

try and keep going and keep up with them instead of telling them about my illness and how I might feel, but now I do" (Dures et al., p.499).

Social support has been shown to be an important factor influencing an individual's ability to adjust to and cope with chronic illness (e.g. DiMatteo, 2004). This is a complex phenomenon, as individuals have different support needs dependent on their circumstances and preference. Research has shown (Duff, 2003) that sometimes social support is lacking if people around the individual do not understand or believe in the impact of the illness, and in a review of research on social support in chronic illness self-management, Gallant (2003) highlighted the potentially negative influences of friends and family. These were described in relation to the social environment, ongoing responsibility and obligations within the family that take precedent over disease management and specific, unsupportive behaviours of friends and family. The latter included a denial of the seriousness of the illness, nagging behaviour, unhelpful advice or the treatment of the individual as an invalid. It is therefore not surprising that participants in the current meta-synthesis experienced the professional support by their therapist and the peer support by others in a group environment as distinct from, and for some preferential to, existing support networks.

Additionally, in a study exploring the values held by individuals with chronic pain, McCracken and Yang (2006) found that participants placed the highest importance on values associated with family and health. It is thus feasible that the opportunity to discuss family dynamics or reflect on illness processes outside of the family context, as reported by participants in this meta-synthesis, confers an additional, important benefit.

"My life has changed so much it's unbelievable" (Dures et al., p.499)

# Theme 6: Therapy as life-changing

Participants in six of the studies described lasting effects of the CBT intervention in their lives beyond therapy. Some participants could identify specific changes, such as an

improved ability to recognise when "personalising" (assuming responsibility for a negative event that is not entirely under the individual's control) (Dennison et al.) and re-engage in activities previously abandoned as a result of the illness (Dures et al.). For others, the change was more widespread: "... it changed my whole attitude on life, changed how I feel about others, changed how I feel about the pain ... I hardly think about it. If it's there, it's there, you know" (Day et al., p.948).

This change was not experienced as a passive process; participants assumed responsibility as active agents in maintaining the skills they had learned and in achieving the balance between accepting the limitations of their physical health status whilst also finding a way to move on: "My way of thinking has changed because of the course. I see that I need to work actively with myself and my situation. I feel that I have started a new chapter in my life" (Furnes et al., p.6).

Specific CBT techniques such as cognitive restructuring have been shown to be important in supporting adjustment to chronic illness (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). The experience of many participants in the current meta-synthesis of long-term positive gains associated with engagement in CBT supports previous qualitative findings of long-term benefits in the context of CBT for chronic pain management (Dysvik, Kvaloy & Furnes, 2013) and in the alleviation of emotional distress associated with cancer (Taylor & Ingleton, 2003).

In a systematic review of studies exploring post-traumatic growth in individuals with a serious physical health condition, Barskova and Oesterreich (2009) found that the quality of social support and individual coping strategies alongside high self-efficacy, self-esteem and optimism were important predictors of post-traumatic growth in the context of illnesses such as cancer, multiple sclerosis and rheumatoid arthritis. The experiences of some participants in the current meta-synthesis could be seen as indicative of post-traumatic growth as a result

of engagement in CBT, as demonstrated by reflections on changing attitudes toward life in general.

#### Conclusion

This meta-synthesis supports existing quantitative and qualitative findings showing that CBT is experienced as beneficial for a range of chronic physical health conditions, based on both model-specific and more general factors relating to therapist qualities and alliance, and social support offered by the therapeutic milieu. Findings in this meta-synthesis add to the existing literature by highlighting the complex nature of perceived social support in the context of chronic illness and specific challenges experienced in relation to CBT in this population. Further research is indicated in which the experiences of individuals who drop out of, or do not benefit from CBT for a chronic physical health condition are explored.

# **Clinical Implications**

This meta-synthesis highlights practical considerations that must be considered when setting up a CBT service for individuals with a chronic physical health condition: physical accessibility of the service, appropriate length of sessions and physical comfort of participants are all potential barriers to engagement that can be easily prevented.

Additionally, illness-specific factors such as the relapse-remitting pattern of some chronic conditions need to be considered as part of the psycho-education component of CBT, in order to ensure that appropriate expectations of potential outcomes for therapy are set from the start. The importance of establishing a good therapeutic alliance is paramount to effective CBT delivery in this context, particularly as this alliance has the additional dimension of offering important social support distinct from that already experienced by family or friends.

# Limitations

This meta-synthesis included studies based on a range of chronic physical health conditions; however there are also several common health conditions that are not represented due to a

lack of qualitative research. It is feasible that different physical illnesses confer differences in experience in relation to provision of social and professional support and at the level of individual illness perception. The decision to include both experiences of group and individual CBT also could be seen as a limitation, although based on the emergent themes across the studies, there was no apparent difference in experience specific to either the physical health condition or mode of CBT delivery. The experiences of individuals who had dropped out of CBT or found it unhelpful were not considered in this meta-synthesis, so the current findings cannot be considered as representative of all experiences of CBT.

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Table 1. Characteristics of selected studies

Authors & Year	Country	Main aim of study	Methodological Orientation	Data Collection & Analysis	Sampling Strategy	Participants	Type of CBT accessed	Context/ Setting
Bottomley., 1998	UK	To explore newly diagnosed patient's experiences of a CBT group for cancer	Not reported	Semi-structured interviews lasting up to 60 minutes  Thematic analysis	Purposive	Gender: 7 x women Mean age 50 years Diagnosis: breast (x 6) or ovarian (x1) cancer Ethnicity: not reported Other: 5 x married, 2 x widowed	8-week outpatient group CBT co- facilitated by a research psychologist and registered counsellor	2 district general hospitals; as part of larger study
Day et al., 2011	USA	To explore effectiveness of CBT as compared to education for chronic pain	Not reported	Semi-structured interviews Thematic analysis	Opportunistic	28 participants in CBT component Gender: approx. 4:1 women:men Mean age 53 Diagnosis: arthritis, headache or other chronic pain condition Ethnicity: Approx. 3:1 African American: White American	10-week outpatient group CBT led by graduate students and/or qualified psychologists	Rural low- income primary care clinics; as part of larger RCT
Dennison et al., 2013	UK	To develop understanding of change processes associated with CBT for multiple sclerosis	Not reported	Semi-structured interviews lasting between 11-127 minutes Thematic analysis	Opportunistic then purposive	15 participants Gender: approx. 4:1 women:men ratio Age:24-64 (mean age 43) Diagnosis: multiple sclerosis Ethnicity: predominantly White British	8-session individual nurse-led CBT via telephone plus 2 x face-to- face sessions	Hospital- based NHS service; as part of a larger RCT
Dures et al., 2012	UK	To explore patients' perspectives on CBT for fatigue associated with rheumatoid arthritis	Not reported	Semi-structured focus group interviews Thematic analysis	Opportunistic	Gender: 30 x women, 8 x men Age: 35-77 (mean age 61) Diagnosis: rheumatoid arthritis for between 1-38 years Ethnicity: not reported	7-session outpatient group CBT	Hospital- based NHS service; as part of a larger RCT

Authors & Year	Country	Main Aim	Methodological Orientation	Data Collection & Analysis	Sampling Strategy	Participants	Type of CBT Accessed	Context/ Setting
Furnes et al., 2015	Norway	To develop understanding of suffering and transition strategies following a chronic pain management programme	Phenomenological -hermeneutic	Semi-structured interviews lasting 40-60 minutes  Interpretative thematic analysis	Purposive	Gender: 9 x women, 3 x men Age: 18-67 (mean age 52) Diagnosis: chronic non- malignant pain lasting more than 6 months Ethnicity: not reported Other: majority unemployed	8-week nurse-led outpatient group CBT	Rehabilitation unit of university hospital
Haraldseid et al., 2014	Norway	To investigate the phenomena of loss in the context of chronic pain and the role of a CBT-based group	Phenomenological	Semi-structured interviews lasting 40-60 minutes  Interpretative thematic analysis	Purposive	Gender: 3 x women, 3 x men Age: 22-65 (mean age 43) Diagnosis: chronic pain Ethnicity: not reported Other: 1 x employed, 5 x parents, 4 x living in relationships	8-week nurse- led outpatient group CBT	Learning and coping centre of a university hospital
MacCorma ck et al., 2001	Australia	To explore patients' experiences of individual CBT versus relaxation therapy for cancer	Grounded Theory	Open-ended interviews lasting 30-45 minutes  Thematic Analysis	Purposive	7 x participants in CBT component Gender: approx. 2:1 women:men Age: 30-72 Diagnosis: metastatic melanoma, breast, or gynaecological cancer Ethnicity: Not reported	6-8 session individual CBT either at home or in hospital	As part of larger investigation by Australia's National Health & Medical Research Council
Matthias et al., 2012	USA	To explore veteran's perceptions of a multicomponent intervention for chronic pain	Not reported	Semi-structured interviews  Thematic analysis	Purposive	Gender: 22 x men and 4 x women Age: 24-62 (mean age 40) Diagnosis: musculoskeletal pain for longer than 3 months Ethnicity: not reported	6-session individual CBT via telephone following medication and 6-session self- management	Veteran Association primary care clinics; as part of larger RCT
Omylinska- Thurston et al., 2014	UK	To identify what patients with primary cancers found helpful in therapy	Not reported	Semi-structured interviews Thematic analysis	Purposive	Gender: 6 x women, 2 x men Age: 36-61 (mean age 50) Diagnosis: various primary cancers Ethnicity: not reported	Average of 12- session individual psychotherapy with CBT with clinical psychologist	Community- based NHS psycho- oncology

Table 2. CASP Quality Analysis

Paper	Clear Aims	Qualitative Justified	Design Justified	Recruitment	Data Collection	Reflexivity	Ethical Issues	Data Analysis	Clear Findings	Value of Research	Total (out of 30)
*Furnes et al.	3	3	3	3	3	1	2	3	2	2	25
Haraldseid et al.	3	3	3	3	3	2	3	3	3	2	28
*Omylinska-T et al.	3	3	2	3	3	3	3	3	3	2	28
*Dennison et al.	3	3	3	3	3	2	3	3	3	3	29
*Dures et al.	3	3	3	3	3	2	2	3	3	2	27
Matthias et al.	3	3	3	3	3	2	2	3	3	2	27
Day et al.	3	3	3	3	3	2	2	3	3	2	27
MacCormack et al.	3	3	3	3	3	2	2	3	3	3	28
Bottomley	3	3	3	3	3	1	2	3	2	2	25

<sup>\*</sup> Indicates papers included in peer audit

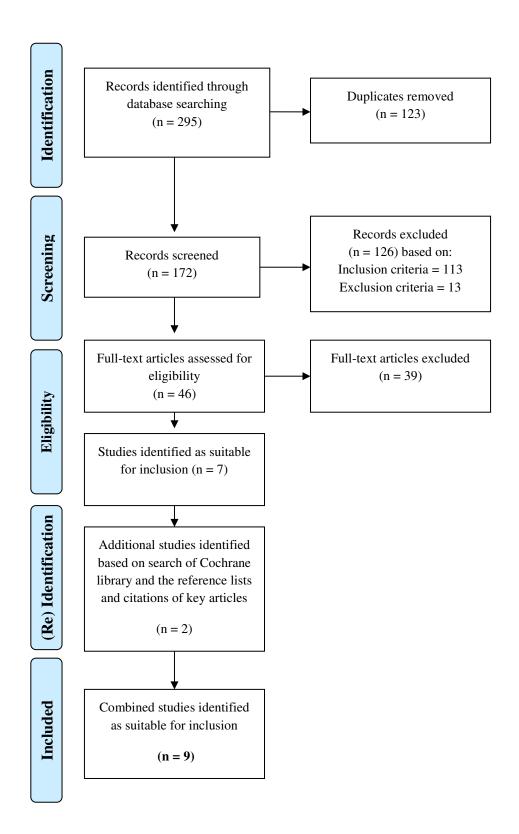


Figure 1. Diagrammatic representation of literature search, adapted from PRISMA flow diagram (Moher et al., 2000).

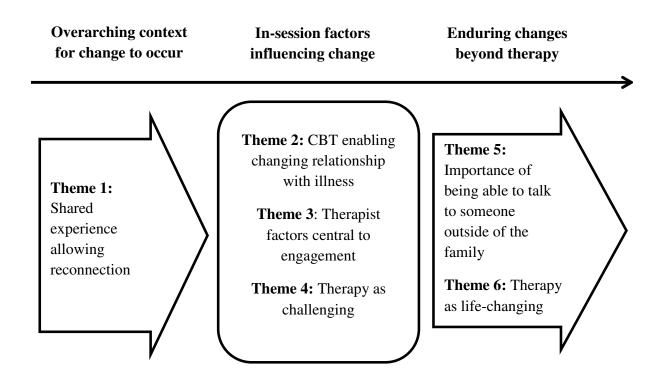


Figure 2. Conceptual thematic diagram.

### Appendix 1-1

### **CASP Checklist Questions**

Was there a clear statement of the aims of the research?
 Is a qualitative methodology appropriate?
 Was the research design appropriate to address the aims of the research?
 Was the recruitment strategy appropriate to the aims of the research?
 Was the data collected in a way that addressed the research issue?
 Has the relationship between researcher and participants been adequately considered?
 Have ethical issues been taken into consideration?
 Was the data analysis sufficiently rigorous?
 Is there a clear statement of findings?

10. How valuable is the research?

# Appendix 1-2

# Excerpt of Coded Data

Dennison et al.	Haraldseid et al.	Omylinska-T et al.	MaCormack et al.
1. Tuning in and sharing	Importance of group	Greater awareness and	Therapy as providing
thoughts & feelings	climate of warmth	understanding of	space to talk about
	and social support	emotional experience:	experiences with
greater self		"I felt I must have saved	someone objective
awareness	Ability to share feelings	up all of the emotional	and outside the family:
	supported by sense of	stuff. Where I should	" It was nice to have
shared experience -	fellowship, trust and	have been higher on my	someone outside the
not alone	understanding:	emotional scale, I	family and not hold
	"We soon gained trust	wasn't and I felt it is not	back about anything. To
feeling heard and	in each other when it	right" (p.86)	be able to actually
understood; valued	was totally clear that		express how I felt, how
	what was being said in	"I would have never	everybody in the family
herapist as objective	the group, remained in	dreamt about sharing	felt about it and not have
outsider permitted	the group" (p.16)	something from my past.	them say 'oh, do you
greater disclosure:		I didn't even know there	really feel like that''' (p.56)
" they were objective,	Trust in each other	was so much anger there	
someone that wasn't	emabled sharing of life	obviously it must have	"The fact that I could open
emotionally involved	stories.	built up from when I was	up to someone (meant) I
with my life I was able		diagnosed with cancer"	wasn't making my
to tell her things I	Sense of shared	(p.86)	husband or my son sad"
probably wouldn't tell	experience:		(p.56)
other people" p.979	"Most of the group	Relief associated with	
	participants dug deep	expressing self:	Therapists as able to
Vallue of having specific	and shared, there were	"Every time I came I	handle hearing difficult
ime and place in which	a lot of tough stories,	would not shut up and	experiences; participants
to think and reflect	and then you see you	if I hadn't have had that	less responsible' for the
	are not the only one to	where would have all	potential impact of their
Increased awareness as	struggle" (p.16)	these words have gone?"	feelings
a result of writing down;		(p.88)	

Appendix 1-3

# Excerpt of Theme Development Table

THEME	SUPPORTING QUOTES & REFERENCES
	<b>Dennison et al.</b> Shared experience - not alone. Feeling heard and understood; valued. Normalising effect of therapy: "You realise that a lot of other people have the same thoughts that you have. And before that I didn't know that other people felt the same way about things as I did" (p.984)
	<b>Haraldseid et al.</b> Importance of group climate of warmth and social support. Ability to share feelings supported by sense of fellowship, trust and understanding: "We soon gained trust in each other when it was totally clear that what was being said in the group, remained in the group" (p.16) Trust in each other enabled sharing of life stories.
1) "So I'm not the only one" Shared	Sense of shared experience: "Most of the group participants dug deep and shared, there were a lot of tough stories, and then you see you are not the only one to struggle" (p.16)
experience Normalising effect of therapy Reduced	Sharing of experiences reinforced sense of fellowship, understanding and acceptance. Importance of social support in feeling understood and supported by another with similar experience: "I recognized myself in everything he said! Everything! It was like: Yes! Yes! Yes!" (p.16)
Isolation	Easier to understand each other if speaking the same 'language' "You feel a companionship, not to whine or complain, but you feel that people know what you mean when you say you have not been able to get into the shower today. People know what it means" (p.16)
	<b>MaCormack et al.</b> Reduced perception of isolation and stigmatisation in relation to the illness: "You don't feel isolated or an outcast, or that they look at you and go, 'Poor thing" (p.56)
	"(not) in this alone. It helped to talk to somebody who talks to people in this situation" (p.56)

"So I'm not the only one who thinks she's going crazy" (p.56)

Sharing experiences via therapist enabled sense of community with people they may never meet but that shared their experience.

**Omylinska et al.** Therapist's knowledge of the emotional processes of adjustment crucial in normalising participants' experiences:

"She was accepting and made me see that a lot of it was very understandable ... normal ... not odd" (p.89)

"You think what's wrong with me ... the therapy has helped with that ... it became clear by the discussions ... that I am not alone in this situation ... the psychologist has seen people in a similar situation before" (p.89)

Relief associated with getting feelings out of the system, offloading, unburdening, getting rid of anger and feeling purged and expressing self:

"Every time I came I would not shut up and ... if I hadn't have had that where would have all these words have gone?" (p.88)

**Dures et al.** Value of working in a group environment in sharing experiences and deriving emotional support from others who understand:

"... It's just extremely useful being able to bounce things off other people and just see how they're managing it" (p.498)

"... you don't feel that it's only you and you are in isolation" (p.498)

**Day et al.** Feeling of not being alone: "It's just good to have someone to talk to and let you know that you're not alone" (p.946)

Sense of community within the group: "... we all looked forward to coming on Friday to sit around, so it just felt like a big family" (p.948)

Furnes et al. Importance of shared understanding within group, whilst also respecting each individual's experience:

1. "So I'm not the only one" Shared experience Normalising effect of therapy Reduced Isolation

### 1. "So I'm not the only one" Shared experience Normalising effect of therapy Reduced Isolation

"When I described how I felt, the other members in the group understood me. I received a lot of encouragement and support. It felt good to open up. There was a nice feeling of community in the group. It was good to share my own thoughts with the others. The leaders woke me up, and they helped me to be able to see life in different ways" (p.5)

"It helped me to express my experiences in the group and still to feel respected..." (p.5)

Increased confidence as a result of perceived safety and contentment within the group.

**Bottomley.** Sense of isolation diminished through shared group experience. Social support conferred by the group environment:

"You all bonded together, all going through the same emotional things and life, death, chemotherapy and whatever else it is and you

just bond together because you're all doing the same thing" (p.27)

Perceived value in allowing space in group for unstructured discussion in addition to CBT material: "Sometimes it would have been nice to talk more as a group, but it was difficult as we had to cover so much, we liked to talk together, particularly at first. We wanted to see each other's problems and share them" (p.28)

# Appendix 1-4

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Personal communication	
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Other reference types	
Patent	Cho, S. T. (2005). <i>U.S. Patent No. 6,980,855</i> . Washington, DC: U.S. Patent and Trademark Office.
Мар	London Mapping Co. (Cartographer). (1960). Street map. [Map]. Retrieved from http://www.londonmapping.co.uk/maps/xxxxx.pdf
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# The Experiences of Clients who Drop-Out of Cognitive Behaviour Therapy (CBT):

### A Qualitative Exploration

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Doctorate in Clinical Psychology

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Prepared for submission to Clinical Psychology & Psychotherapy

#### Abstract

CBT is the dominant psychotherapy model for a range of mental health difficulties. Although there is clear evidence for its effectiveness for many individuals, there are also those for whom CBT is unhelpful. This study aimed to provide an account of the experiences of adults who have dropped out of individual CBT in a community setting in the UK. A semi-structured interview was carried out with 11 participants who had accessed CBT for support with various difficulties. Thematic analysis resulted in the development of five themes: the role of therapist factors, limitations of the CBT model, CBT as pathologising, the socio-political context of CBT, and responsibility for engagement and change. This study is the first to explore CBT drop-out across diagnostic categories, from within a qualitative design. The findings have implications for all professionals delivering CBT, including the need for greater consideration of choice and flexibility of psychosocial interventions, and recognition of the potential impact of clients' awareness of the socio-political context of CBT on their ability to engage in therapy. Further areas for research include qualitative exploration of both client and therapist experiences of therapy drop out, and exploration of the experiences of non-psychology professionals who deliver CBT in the community.

### **Key Practitioner Message:**

- There exist several barriers to successful engagement in CBT, in relation to individual factors, therapist factors and the socio-political context.
- Services need to consider the appropriateness of CBT as an intervention, based on individual need and therapist competence.
- Further training of non-psychology staff in CBT is indicated and should include an emphasis on development of therapeutic alliance.

**Keywords:** CBT, cognitive behaviour therapy, experiences, qualitative, drop-out, therapy.

The Experiences of Clients who Drop-Out of Cognitive Behaviour Therapy (CBT):

# A Qualitative Exploration

CBT was initially developed by the psychiatrist and cognitive therapist Aaron Beck in the 1960s, as a "structured, short-term, present-oriented psychotherapy for depression, directed toward solving current problems and modifying dysfunctional thinking" (Beck, 2011, p.2). The 'generic cognitive model' proposed by Beck and Haigh (2014) conceptualises psychological distress as a result of "faulty information processing ... leading to thinking errors" (p.4) and "negatively biased schemas" (p.5), which cause individuals to hold negative and distressing beliefs and assumptions about themselves, others and the world. CBT therefore involves various tasks aimed at challenging these cognitive biases and changing associated behaviour, with the aim of reducing psychological distress. CBT can be delivered by a range of qualified practitioners and in different formats; which include individual therapy, group therapy and via computer.

CBT occupies a dominant position in comparison to other psychotherapy models within best practice clinical guidelines for the treatment of common psychiatric diagnoses, such as those produced by the National Institute for Clinical Excellence (NICE). The American Psychiatric Association (2010) also recommends CBT in the treatment of depression; although it does highlight the importance of the preference of the individual in selecting both pharmacotherapy and psychotherapy approaches. Extensive research has highlighted the effectiveness of CBT in providing symptomatic relief for a wide range of mental health difficulties, as demonstrated by a recent review of 106 existing meta-analyses (Hofmann, Asnaani, Vonk, Sawyer & Fang, 2012).

The evidence-based practice model of healthcare delivery has grown in

prominence in western countries, in response to rising healthcare costs, a greater awareness and availability of targeted interventions for various psychiatric diagnoses and an increase in research to support these approaches (Huppert, Fabbro & Barlow, 2006). Difficulties associated with mental health diagnoses such as depression and anxiety represent one of the most significant public health challenges in these countries, as measured by prevalence, burden of disease or disability (World Health Organisation, 2013).

In the UK, the 'Improving Access to Psychological Therapies' (IAPT) government-funded programme was developed between 2005 and 2008, in order to provide support in the form of talking therapies (predominantly CBT), in primary care settings for individuals experiencing depressive and anxious symptoms. Two key drivers for IAPT implementation were to reduce public spending in the form of welfare benefits and medical costs and to increase revenue through taxes from return to work and increased productivity (Department of Health, 2012). As a government-funded project, a key component of IAPT has been outcome measurement using session-by-session symptom-based questionnaires, in order to provide a rationale for its continued implementation.

The evidence-based practice movement has been criticised for placing too much emphasis on treatment factors in measuring effectiveness, rather than a broader consideration of other influences on treatment outcome, such as therapist characteristics or the subjective experience of the treatment recipient (Wampold & Bhati, 2004). A review of findings from various task forces associated with evaluating and disseminating information about the progress of evidence-based practice in psychotherapy (Chambless & Ollendick, 2001) highlighted several important factors: a

relative reliance on quantitative research to evaluate psychotherapy efficacy, a high proportion of manual-based approaches, questionable generalisability of research findings to clinical populations and whether treatment specificity is a valid construct.

Previous research into therapy effectiveness within and between different therapeutic models has proposed a 'common factors model' by which there exist "a set of factors that are common to all (or most) therapies ... and ... these common factors are responsible for psychotherapeutic benefits rather than the ingredients specific to the particular theories" (Wampold, 2001, p.23). These common factors have been classified by Lambert and Ogles (2004) as relating to support (therapeutic alliance), learning (feedback and insight) and action (modelling and practise). Extensive research supports the common factors model, particularly highlighting the importance of the therapeutic alliance in predicting outcome (e.g. Martin, Garske & Davis, 2000). A study by Gega, Smith and Reynolds (2013) compared service user experiences of computerised versus therapist-delivered CBT and found that participants favoured therapist involvement as this felt more individualised, human and less isolating. Interestingly however, a recent meta-synthesis of qualitative research exploring user experiences of computerised CBT (Knowles et al., 2014) highlighted mixed perceptions of service users in relation to the absence of therapist presence and support, as some derived a sense of empowerment and mastery from engaging in therapy independently; whereas some experienced isolation and helplessness.

Despite a clear indication for the presence and central influence of common factors in predicting therapy effectiveness, the majority of research in the context of evidence-based practice has continued to focus on exploring the effectiveness of distinct therapeutic models, such as CBT. As CBT is based on the premise that 'problems' are

cognitively mediated and can thus be ameliorated by modifying dysfunctional thoughts and beliefs (Dobson & Dozois, 2001), the model lends itself to quantitative, experimental investigations, based on a medical model of symptom reduction as an indicator of successful outcome. This was evidenced in a review of 16 meta-analyses of CBT effectiveness (Butler, Chapman, Forman & Beck, 2006), all of which used specific symptom measures as evidence of effectiveness.

In addition to studies exploring therapy effectiveness, some researchers have sought to explore the phenomenon of therapy 'drop out' - a concept that has been conceptualised in several different ways within existing research. Based on their literature review exploring drop out from family and marriage therapy, Werner-Wilson and Winter (2010) identify three definitions:

- 1) The client fails to attend a specified number of sessions, regardless of outcome.
- 2) The client chooses not to continue as they believe that their goals have been met.
- 3) The client terminates therapy without having fulfilled their therapeutic goals, regardless of how many sessions or length of time they have already spent in therapy.

There is overlap between these definitions; however the main distinction is the relative responsibility or power attributed to the therapist and client in each, in deciding when and how to drop out.

Recent research findings have indicated that approximately 20 percent of individuals drop out of therapy before the predetermined timeframe has elapsed (Swift & Greenberg, 2012). Several reasons for this have been suggested: the way therapy is delivered and systemic context, for example, inherent pressure associated with an inpatient environment (Chiesa, Drahorad & Longo, 2000); financial constraints and

other life demands (Swift & Greenberg, 2012); and therapeutic rupture, whereby conflict arises between client and therapist (Knox et al., 2011).

In a quantitative study exploring the views of both clients and therapists,
Westmacott, Hunsley, Best, Rumstein-McKean and Schindler (2010) found that
contextual factors (as described above) had differing levels of influence, depending on
whether the decision to terminate was made independently by the client, or as a result of
a mutual agreement between client and therapist. Independent decisions tended to be
based largely on circumstantial barriers or issues with the therapist or therapy, whereas
mutual decisions were predominantly based on attainment of therapy goals.

Two studies have directly explored clients' views on individual therapy drop out using a qualitative design. Knox et al (2011) interviewed 12 clients about their experiences of premature termination from individual therapy. As recruitment was largely via the researchers' professional networks and academic contacts, eleven of the participants had training at Masters or Doctorate level in a mental health profession. Five of the participants described their termination from therapy as based on practical or financial constraints rather than a negative experience of therapy. The other seven participants described a generally positive experience of the therapy, but reported that negative experiences of the therapist or therapeutic relationship, for example not feeling listened to or perceiving the therapist as pushing their own agenda, ultimately led them to terminate therapy abruptly and without discussion with their therapist. The findings were limited by the restricted nature of the participant characteristics and the inclusion of a range of therapy approaches, which means it is difficult to establish whether individual experiences were due to the model of therapy experienced or other factors.

Piselli, Halgin and MacEwan (2011) conducted a qualitative exploration of the experiences of therapists when clients terminate therapy prematurely. Eleven clinical psychotherapists were interviewed, who identified themselves as using an eclectic or integrative approach (the authors chose to dissociate the research from any particular theoretical orientation or therapy model). Participants were asked to describe an experience of premature therapy termination based on a client "whose primary diagnosis was not an Axis I psychotic or substance abuse disorder or an Axis II personality disorder" (p. 403). Findings indicated a range of explanations for premature termination, which were classified as factors relating to the client's experience of therapy, circumstantial barriers, the therapist or the therapeutic relationship.

These studies explored therapy drop out across client populations and therapeutic models. There exists only limited research into client drop out from CBT specifically, and of that research, the majority of published studies have focused on quantitative outcomes. In a literature review based on 14 of these studies, Salmoiraghi and Sambhi (2010) highlighted the contention between different findings, in relation to the potential influence of demographic variables such as age, gender, socio-economic status and diagnosis in predicting drop out from CBT. They also found that only two studies had reported practical and circumstantial constraints as a reason for drop-out and only one study had reflected the influence of therapist factors.

Two qualitative studies have explored individual experiences of CBT drop-out in more depth. In an Australian study, Dunn, Delfabbro and Harvey (2012) interviewed five clients via telephone to explore their experiences of premature drop out from CBT for problem gambling. Dunn et al. found that unexpected lifestyle changes and (lack of) readiness to engage and change were a key aspect of participants' experiences.

Additionally, some clients had terminated therapy prematurely as they felt that they had learned sufficient skills to continue. These findings were conceptualised within the theoretical framework of problem gambling and as such, cannot be generalised. However, the qualitative nature of these direct shared experiences offered new insights into factors influencing therapy drop out.

Barnes et al. (2013) utilised a mixed-method approach by which, as part of a broader randomised controlled trial investigating the use of CBT as an adjunct to pharmacotherapy for treatment-resistant depression, they interviewed 26 clients who had dropped out of therapy. Findings were grouped into themes based on in-session factors and the homework component of CBT. In-session factors contributing to CBT drop-out included a belief by participants that the cause of their depression was not adequately explored, difficulty in discussing their experience and an inability to relate to the therapist. Interestingly, some participants experienced chronic physical health conditions as a barrier to engagement in CBT, despite research evidence for the model's effectiveness for chronic illnesses (e.g. Hoffman, Papas, Chatkoff & Kerns, 2007). Homework factors included negative emotional responses, such as a fear of failure, reinforced by an association with previous homework at school, or distress associated with recognition about causes of depression. Participants also described homework as an isolating, unsupported experience that could be overly prescriptive in format. The study was limited in only exploring the views of individuals with a diagnosis of depression and in its context as a research trial.

The relative lack of qualitative research into service user experience of psychotherapy such as CBT, in the context of increasing pressure in western countries to deliver evidence-based interventions means that any research that aids our

understanding of this phenomenon is both necessary and timely. The aim of this study was thus to contribute towards addressing the gap by exploring the direct experiences of clients who had prematurely dropped out of community-based, face-to-face CBT, outside of a research trial context and not limited to users of NHS services.

### Method

## Design

The study used a qualitative design, based on semi-structured interviews, so as to enable a rich exploration of the lived experience of individual participants. The aim was to recruit a broad range of participants, with different backgrounds and experiences of CBT, in order to explore shared and contrasting accounts of CBT drop-out across different mental health services in the UK.

## **Participants**

The researcher aimed to recruit between 8 and 12 participants for the study, based on suggested guidance for qualitative research proposed by Guest, Bunce and Johnson (2006). The following inclusion and exclusion criteria were used:

### Inclusion criteria.

Male and female adults in the United Kingdom, who had accessed individual CBT in the last ten years for any mental health need, in a community-based setting with any qualified therapist, and who had independently chosen to disengage from the therapy prematurely (i.e. before the end of the predetermined timescale).

### **Exclusion criteria.**

1) Individuals for whom English was not their first language, and who would thus require access to translation services. Although acknowledged as a limitation of

- the study, it was recognised that the use of translators may significantly influence the accuracy, richness and content of the data obtained.
- Individuals who had accessed self-directed or computerised CBT or CBT via telephone appointments.
- Individuals who had accessed CBT in non-community settings e.g. inpatient or forensic.
- 4) Individuals who were unable to participate in the interview process (either via telephone or in person).
- 5) Individuals who had engaged in therapy other than CBT, CBT with a group-based component or a mixed-model approach.
- 6) Individuals who were actively distressed at the time of the interview.

### Recruitment

Participants were recruited via the following means:

- Written adverts on several online mental health support forums across the UK.
- Written adverts on the main researcher's Twitter account (dedicated account created for the current study).
- An e-mail advert to peers and colleagues of the main researcher, with a request to circulate to anybody who may potentially be interested.

The advert for the study (see appendix 2-A) included contact details for the main researcher, who sent out a participant information sheet and consent form (see appendices 2-B and 2-C) to each participant. A total of 18 potential participants contacted the researcher for further information about the study. Of these, two were excluded based on the exclusion criteria and five did not respond to a follow-up e-mail; thus 11 participants were interviewed for the study.

### **Participant Characteristics**

Of the 11 participants, seven were female and four were male, with an age range from mid-twenties to mid-forties at the point that they had accessed CBT. Several geographical locations across England were represented. The majority of the participants had accessed CBT within the last five years, within an NHS primary care service. There was variation in the reasons for accessing and dropping out of CBT and in the therapist qualifications. Eight of the participants had experienced previous mental health difficulties, and three had prior therapy experience. A more detailed summary of each participant can be found in table 1 and appendix 2-D.

[Table 1 near here]

### **Ethics**

Ethical approval was sought and obtained from Lancaster University Faculty of Health and Medicine Research and Ethics Committee. Some initial amendments were made prior to final approval, which included widening recruitment to the whole of the UK and offering face-to-face interviews in participants' homes within a limited radius of the University. Full ethics documentation can be found in section 4 of this thesis.

#### **Data Collection**

Each participant was interviewed by the main researcher and the interviews ranged in length from 22 to 44 minutes (the average interview length was 32 minutes). The interviews were semi-structured and loosely based on a topic guide (see appendix 2-E) in order to ensure that key aspects of the research question were explored with each participant, whilst also allowing space for each participant to speak about the important aspects of their individual experience. A general overview of the interview topics is as follows:

- Descriptive and background information
- Experience of CBT in relation to the therapy model and therapist characteristics
- Reasons for dropping out
- Subsequent therapy experience

# **Data Storage**

Interviews were audio-recorded, then saved following each interview within an encrypted folder on the University pass-protected shared drive, at which point the files were deleted from the recorder. Hard copies of consent forms were scanned electronically and submitted to the DClinPsy research coordinator for storage on the University pass-protected shared drive, following which the hard copies were securely destroyed.

## **Data Analysis**

The interviews were transcribed and then coded based on key content of the interview text (see appendix 2-F for excerpt of coded transcript). The 431 initial codes generated from the transcripts were then collated into themes (see appendix 2-G, for example), based on shared concepts and experiences between participants and informed by the approach suggested by Braun and Clarke (2006). An inductive approach was taken throughout the analysis, as although the researcher did have some preconceived ideas based on existing research findings as to broad themes that may be present, the relative lack of existing qualitative literature on CBT drop-out enabled analysis to be largely data-driven. It is important to note that by adopting an inductive approach and with the aim of representing the participants' experiences as purely as possible, individual accounts were taken at face value and as such, cannot be generalised beyond the individual, subjective view of each participant.

### **Results**

Analysis of the interviews resulted in five major themes:

- 1. The role of therapist factors
  - Sub-themes: Lack of collaboration, therapist as a barrier, therapist as incompetent, therapist as human.
- 2. Limitations of the CBT model

Sub-themes: CBT as present-focussed, CBT as time-limited, CBT as prescriptive, CBT as challenging.

- 3. CBT as pathologising
- 4. The socio-political context of CBT
- 5. Responsibility for engagement and change

Sub-themes: Motivation and readiness to engage, internal vs. external attributions of blame, responsibility to therapist.

The most prominent and recurring issues related to the first two themes, reflecting existing research findings which highlight the importance of both model-specific and therapist factors as influencing engagement in psychotherapy. Many of the participants also spoke about how they had experienced CBT as pathologising and overly problem-focused (theme 3), which had further impacted on their ability to engage with the model and therapist.

Interestingly, over half of the participants spoke about their awareness of the socio-political context of CBT (theme 4) in relation to the government agenda behind NHS primary care mental health services. For some, their views on this had caused them to have negative preconceptions of CBT and the potential usefulness of the model, which had increased the likelihood of drop-out independently of the above three themes.

Perceptions of CBT as primarily driven by the objective of reducing unemployment also reinforced participants' view of CBT as pathologising and impersonal.

The final theme reflected participants' recognition of the role of individual motivation and readiness to engage in therapy in influencing their subsequent experience of CBT and relationship with the therapist and thus influenced participants' experiences of the first three themes.

# Theme 1: "She was just human!" – The role of therapist factors

This was the theme with the largest amount of data, as all of the participants highlighted the crucial role that the therapeutic relationship had in their ability to engage in CBT. This was clearly summarised by one participant:

CBT as a therapy style can be very mechanistic, which isn't a bad thing in itself, but it leaves a gap in terms of, you know, therapeutic relationship because you can teach CBT without touching the other person, without any kind of emotional involvement (Luke)

Interestingly, Luke had also spoken about his background as an engineer and his preconception that CBT would be helpful due to the model's "clear process", rather than therapist factors, whereas this perception was adjusted as a result of his experience of CBT.

### Lack of collaboration.

The importance of collaboration was emphasised by several participants.

Several were critical of the non-collaborative approach taken by their therapist, as they perceived that they had been "hardly involved ... it felt more done to me" (Jack) or had been "told what was going to happen" (Stockley). Perceived lack of collaboration made it more difficult for participants to engage in CBT, even when they had experienced the

therapeutic relationship as positive: "it maybe felt more collaborative in that we were being in a room together rather than that I was an active partner moving towards some sort of solution or something" (Zesty) and:

she just- made me more of a participant, I mean it wasn't done in a erm a divisive way, she was perfectly you know nice, but I think you have to have a bit more of a partnership, bit more erm *we* are doing this, you know and this is how *we* are going to do it (Jimmy)

The contrast between perceived collaboration, whereby "she'd try and find a workbook for each week suited to my needs" (Becky) and a more directive approach "like we were following her agenda of how to do things and ... she hadn't explicitly said why we were doing things a certain way" (Natalie) was highlighted as a contributing factor to several participants' decisions to drop-out.

## Therapist as a barrier to engagement.

For over half of the participants, the therapeutic relationship was experienced harmfully due to negative qualities associated with the therapist, rather than a lack of collaboration: "you need someone understanding and sort of gives you positive feedback, but she didn't have that" (Caz). Therapist motivation was questioned by one participant: "she did just seem like she didn't really care about you as an individual, it was just a job" (Joanne). For two of the participants, their perception of the therapist as dismissive or attacking was the direct reason for CBT drop-out: "it got to the point where I didn't - I didn't want to say anything because I felt like whatever I said it would kind of be attacked" (Natalie) and "I felt I just couldn't talk to him about anything and felt the therapist wasn't interested in erm- in what I had to say" (Katie). Katie also spoke about an example of an inappropriate metaphor the therapist used, in highlighting

their lack of understanding of individual need: "I remember him saying that you need to push yourself as if erm as if you're playing a game of tennis ... I remember thinking well I don't actually play tennis ..."

## Therapist as incompetent.

In addition to issues around perceived lack of collaboration and negative therapist qualities, two of the participants spoke about their perception of the therapist as insufficiently competent or intelligent as a barrier to engagement. This was experienced by Natalie as a reduction in confidence in the therapist's ability to deliver CBT: "I felt like her understanding of it was probably only about as good as mine." Zesty experienced this as an interpersonal difference affecting their ability to relate to and respect the therapist:

I think she probably thought I was a bit er of a handful and I think I probably thought she was a little bit dull and perhaps not the brightest therapist I'd ever spoken to, but erm she was- she was not offensive in any way.

Both of these participants had received therapy from a mental health nurse with some CBT training, so this may reflect a broader issue around inadequate training and supervision of some staff in primary care services.

## Therapist as human.

In contrast to these negative experiences of therapist qualities and their approach, two participants commented on their positive experience of appropriate therapist disclosure ("she was just human!" (Lisa)) in helping them to engage in therapy: "We'd found these common grounds in exploring my life ... she was, very rare for a therapist I found, she was happy to disclose things which were common between us" (Luke), and:

She just gave a few ... personalised ... examples and that helped me so much, like to this day I still think about that ... she could have chosen not to give anything of herself ... it was that sort of human quality about her ... not this pan-faced, 'I'm not going to tell you anything about myself' (Lisa)

The importance of the therapeutic alliance in facilitating engagement in psychotherapy has been highlighted in several research studies (e.g. Martin, Garske & Davis, 2000), and there is evidence (Wampold, 2006) that the individual characteristics of some therapists mean that they are more successful than others, irrespective of the therapy model they are delivering. A review by Ackerman and Hilsenroth (2003) highlighted specific therapist attributes that have been shown to contribute to the development of a positive alliance, which include flexibility, warmth, showing interest, confidence and honesty. These findings were supported by participants' experiences in the current study. Poor therapeutic alliance has also been associated with a greater likelihood of therapists deviating from the CBT model in an attempt to maintain client engagement (Zickgraf et al., 2015).

The majority of the participants in the current study had accessed CBT in an NHS primary care service. The Department of Health has published guidelines on general and specific competencies for CBT therapists in these settings, which include an appropriate knowledge base and an ability to develop a positive therapeutic relationship, defined as "a trusting relationship with (their) clients, relating to them in a manner which is warm, encouraging and accepting (Roth & Pilling, 2007, p.8). It is apparent from some of the participants' accounts that this was not achieved by all of the therapists that they encountered, which perhaps raises a question as to the nature of

training received by therapists in these services, particularly those who do not have an existing background in delivering psychotherapy.

Therapist self-disclosure in CBT has also been shown to be an appropriate and effective means of supporting the therapeutic relationship and between-session changes (Goldfried, Burckell & Eubanks-Carter, 2003). Goldfried et al. describe two types of therapist self-disclosure: the disclosure of personal reactions to the client in-session, as a means of behavioural reinforcement, or the disclosure of personal information about the therapist's life outside of the sessions, as a means of cognitive-behavioural modelling. The experience of some participants (e.g. Luke and Lisa) in this study supports the positive benefit of appropriate therapist self-disclosure in promoting a healthy therapeutic alliance.

Collaboration between therapist and client is one of the underlying principles of CBT and has been described as "a cooperative effort between therapist and patient in devising a treatment plan and incorporates cohesiveness between the patient and the therapist as they explore together through discovery and experimentation those aspects of the patient that contribute to dysfunction" (Dattilio & Hana, 2012, p.148). It is therefore surprising that so many of the participants in the current study experienced a lack of collaboration and perhaps reflects the relative ability of individual therapists to promote a collaborative ethos, whilst also adhering to the key underlying principles of the CBT model.

# Theme 2: "It just seemed like a box-ticking exercise" – Limitations of the CBT model

In the second largest theme, all of the participants spoke about their perceived limitations of the CBT model as a factor influencing their eventual drop-out. This was

experienced in relation to the four sub-themes: CBT as restricted in focussing solely on the present problems and context, CBT as time-limited, CBT as prescriptive and impersonal and CBT as challenging.

### CBT as present-focussed.

Several participants described how they felt that CBT did not explore enough about the past context of their difficulties, for example: "(it) wasn't looking at why I had the issues I did" (Katie) or "(considering) how issues in my past might be kind of having their influence now" (Stockley). However, one participant did have an opposing view and felt that the present-day focus of CBT was helpful: "being able to acknowledge that that had happened but not have an expectation to talk it through in detail at that moment in time was preferable to me" (Natalie).

### **CBT** as time-limited.

The time-limited nature of CBT was highlighted by many of the participants as an issue with the model, in that "it just didn't feel genuine" (Jack) or instil confidence in participants' ability to make meaningful changes: "I can't sort of unravel like 30 years of trauma in like just a few sessions" (Katie). For Zesty, this negatively influenced her motivation to engage in CBT: "I think I sort of lost interest a bit because actually those things couldn't really be answered in six sessions, by someone who didn't really know me at a quite busy clinic."

# CBT as prescriptive.

Several participants described their perception that the concepts underpinning CBT and the way the model was delivered felt judgemental or overly prescriptive, in making "an awful lot of assumptions about people" (Stockley). CBT was also described as "a box-ticking exercise" (Jack), which did not inspire confidence. This

was experienced by Katie quite personally, as if CBT "says that people need to change cause they're not acceptable the way they are" and summarised by Jack as:

I didn't feel it was meaningful to me or the issues that I was feeling and I don't feel it ... made any attempt to connect with those, it was more ... generalised and ... it seemed to come across like it was telling me 'oh all you have to do is think like this, and then you'll be fine' and uh 'we'll be done in a couple of sessions.'

## CBT as challenging.

These factors, alongside therapist factors, led many of the participants to experience CBT as difficult or challenging. One participant experienced this in particular relation to the cognitive restructuring aspect of CBT: "the idea that ... you could almost block a bad view of a situation, just felt disingenuous, I just felt despair about not feeling real, you know?" (Luke). Another participant described how she had experienced CBT as "a bit too succeed or fail" (Katie). A lack of rationale by the therapist in setting up difficult tasks contributed to participants' perceived ability to overcome challenges: "there wasn't enough of an explanatory kind of buffer if you like, to say that's got to happen" (Jimmy).

Participants' experiences of CBT as overly present-focussed and prescriptive reflect findings from existing research. In a study comparing qualitative experiences of change associated with CBT versus psychodynamic psychotherapy, Nilsson, Svensson, Sandell and Clinton (2007) found that some participants who had engaged in CBT had experienced specific change in relation to presenting problems; however this was not achieved for other participants who had experienced CBT as rigid and restrictive. In their mixed-method study, Barnes et al. (2013) found that participants described CBT as

lacking in depth of understanding by not allowing for exploration of historical factors, and also that the inflexibility of the CBT model prohibited meaningful engagement.

Research has highlighted the role of emotion in CBT (Samoilov & Goldfried, 2000), as a barrier for some individuals who can understand their difficulties at a cognitive level, but cannot experience any change in associated emotional affect through CBT techniques. This reflects the experiences of 'Jack' and 'Luke' in the current study, who experienced CBT as predominantly cognitively-focussed and unable to reach them emotionally.

An important consideration is the overlap between this theme and the first theme around participants' experiences of the therapeutic relationship, as it was apparent from the interviews that, in the context of a positively-perceived relationship, some of the limitations or challenges associated with the CBT model could be overcome.

Interestingly, many of the participants in the current study went on to engage in an alternative form of psychological therapy after dropping out of CBT, which they reported as more helpful. In a qualitative study comparing user experiences of CBT and psychotherapy, Gostas, Wiberg, Neander and Kjellin (2012) found that participants experienced the CBT therapists as occupying an active, guiding, explanatory role, whereas the psychodynamic psychotherapists listened, contained and interpreted both past and present context. These characteristics could be seen as representing both model-specific and therapist factors and reflect the experiences of participants in the current study.

# Theme 3: "Ticking their symptoms" - CBT as pathologising

All but two of the participants spoke about their experience of CBT as pathologising their mental health. This was experienced as: a perception of CBT as

diagnosis-driven and problem-focussed, CBT as exacerbating existing difficulties or creating new problems, and a recognition of the positive impact of contextual changes outside of the CBT.

Three participants reflected on the negative influence of CBT as problemfocussed - "I felt that I was ticking their symptoms that's all" (Katie) - and as contingent
on a diagnosis: "... it's just like well of course, to access this psychological therapy you
must be ill, you must have this" (Lisa). Lisa was only made aware that she had received
a diagnosis after the CBT had ended, which informed her retrospective view of the
therapy: "I can imagine I got the CBT because of that- that diagnosis on piece of paper,
based on those scores I answered on that first assessment." For Natalie, her perception
that the therapist was trying to fit her experience to a particular diagnosis negatively
influenced her ability to engage in the CBT: "I was also worried about saying the wrong
thing ... because she seemed to be looking for diagnoses I think, and I felt like if I say
this it's going to imply that I have a particular diagnosis."

Several participants spoke about the outcome measures in CBT as generic: "sometimes I didn't really want to answer that ... it felt a bit excessive ... some of the questions ... weren't really relevant to what I was actually there for..." (Becky) and overly simplified: "I just feel we're a bit more complex than a quick happiness scale ... it's too quantifiable ... it's more open to manipulation and interpretation on the opinion of whoever's collecting the data" (Jack).

Two participants spoke about the negative impact of CBT in either creating a "new problem that I wouldn't have had before" (Katie) or by exacerbating existing difficulties, due to the focus on identifying and changing cognitions: " ... (I) rose into depression again, which could have been led by CBT, thinking those thoughts, I'm sure.

Each week I would come out with a thought like 'I wish I could have', or 'I'm useless'" (Luke).

Another key aspect of this theme was participants' recognition that, sometimes, difficulties were the result of "normal worries" (Lisa) and thus could improve or resolve outside of therapy, if life circumstances changed:

I think because the waiting list had been so long, I think I was actually doing a bit better... actually just living with somebody full-time had actually fixed the eating issues because suddenly food was showing up on my plate at regular times. (Zesty)

Rather than acknowledge and normalise this process of natural change, CBT was perceived as unhelpful in attempting to pathologise difficulties, by conceptualising problems from within a symptom-based, diagnostic framework.

The 2013 European Mental Health Action Plan (WHO) highlighted the growing recognition for the need to consider mental health difficulties in the wider context of psychosocial and cultural influences, to consider individual strengths and assets as well as difficulties and to move away from single intervention approaches. Existing research has shown that for some individuals, their difficulties can resolve independently of psychotherapy, in response to life changes (e.g. Dunn, Delfabbro & Harvey, 2011). This was supported by the experience of several participants in the current study, who found CBT obstructive in attempting to locate the 'problem' at an internal level, rather than in the context of environmental pressures, or who experienced a reduction in difficulty and distress in response to naturalistic life changes, rather than as a result of CBT techniques.

The British Psychological Society (2014), highlight the controversies and limitations associated with reliance on psychiatric diagnosis in shaping mental health services, and the questionable role of diagnosis in facilitating research based on specific models of psychotherapy. The authors criticise the medical model in not allowing for adequate consideration of social and psychological factors in conceptualising distress and behaviour in mental health contexts. These concerns are reflected in the experience of several participants in this study, in their perception of CBT as unnecessarily pathologising and reductionist as a model.

# Theme 4: "A stick to beat people with" - The socio-political context of CBT

Over half of the participants spoke about their awareness of the socio-political context of CBT within the UK, as "something that's preferred from a business point of view" (Jack). For Stockley, his views on the government agenda of CBT had negatively influenced his ability to engage from the start:

... the political context of CBT being used by the government as kind of a stick to beat people with, so you will do CBT or you will potentially lose your benefits or you know, if you don't accept CBT or you decide not to do CBT then you're not doing everything you can to get better.

Lisa spoke about her surprise and anger at finding out that, in order to access CBT, she had been given a mental health diagnosis that she had not been aware of until finishing the therapy "... I appreciate that's how the system works, but it shouldn't."

For some participants, systemic factors associated with service-level policies on CBT delivery had contributed to their experience of CBT. Joanne had been forced to drop-out of CBT on two separate occasions, due to the "no-strike rule" around missed appointments in her local service. Other participants commented on the outcome

measures used, as being numerous "... there was often three questionnaires, it felt a bit excessive" (Becky) or tokenistic to the therapy process, as "the questionnaires weren't even in the session, 'cause they were just given out in the waiting room" (Zesty).

Overall, there was a clear message in all participant narratives that "... different things might work for different people and ... listening to what works for the person is important" (Katie). The limited choice of therapy offered in NHS services had caused some participants to feel dismissed by mental health services if unable to engage or benefit from CBT: "... well you've tried this and now you're back to being on your own with the illness" (Stockley). For Luke, awareness of the relative lack of alternative options to CBT had caused him to persevere with CBT, despite finding the model detrimental to his well-being: "I was desperate for something, I was desperate for some sort of therapy, some sort of involvement from services ... and I wouldn't really let go of CBT."

The extent to which participants were aware of and able to critically engage with the socio-political context of CBT delivery in the UK was an unexpected outcome of the current study. The detrimental impact of this on participants' preconceptions of, and engagement in, CBT was apparent in their narratives. This perhaps also reflects the inevitable dilemma faced by some clinicians practising in services underpinned by an evidence-based model, in having to adhere to a particular model regardless of service user preference. Research has shown (Leykin & DeRubeis, 2009) that the extent to which the therapist believes in and advocates for the therapy model they are delivering can have an impact on how effective the therapy is. This has implications for clinicians working in primary care settings for whom CBT may not be their preferred therapy model. This could also explain the perception by some participants in this study that

their therapist was lacking in motivation or interest. Research has shown (Ackerman & Hilsenroth, 2003) that inflexibility and dogmatic reliance on a specific therapy model that is incompatible with service user needs can lead to treatment breakdown. The current findings thus support the existing argument for a more flexible approach to mental health service delivery in primary care settings.

Another key finding within this theme was participants' views of the outcome measures used in CBT as largely irrelevant, unnecessary and excessive in nature. In the UK, therapy effectiveness is measured at national level in relation to a reduction in generic symptom-based standardised questionnaires, rather than by more idiosyncratic personalised methods. This approach has been criticised (e.g. Roberts, 2000) for reducing individual experiences of meaningful change to a rigid, medicalised model. Several participants in the current study shared this view (as discussed above) and found the method of outcome measurement obstructive and impersonal. Furthermore, some participants felt an obligation to their therapist to misrepresent their subjective experience on the measures, as is apparent in the next theme.

# Theme 5. "You can't just expect miracles overnight" - Responsibility for engagement and change

The final theme reflects the recognition by all participants of the impact of their readiness to engage and change at the point they accessed CBT on their subsequent decision to drop out.

### Motivation and readiness to engage.

Some participants recognised that they had a degree of ambivalence at the start of therapy, for example: "my heart wasn't really in it" (Jack); or that they had questioned "whether it was ever going to be effective for me given my particular biases"

(Stockley). The impact of other people in driving a referral to therapy, perhaps not at an appropriate time for the individual was also highlighted by Becky: "I knew that I needed to change something but I feel that maybe I was a little bit pushed into seeking help at that point."

Other participants reflected on how they had only considered the influence of their own motivation and readiness to engage in hindsight, once they had dropped out: "I think I was at a time where I was too sensitive to be able to cope with it ... I was struggling to take things in and that may have been the case no matter who the practitioner was" (Natalie) and "I think age plays a part in it ... whereas the first time, it was kind of 'hmm I think I can do without this, I can manage' whereas the second time around was like 'no I've got to do everything I can to fix this" (Jimmy).

### Internal versus external attributions of blame.

Individual readiness to engage was also linked to participants' experience of feeling that they were to blame if the CBT was ineffective. Preconceptions of CBT as effective, based on participants' existing knowledge, contributed to a sense that the model should work for everyone: "everyone says that ... it's good and I think that ... belief has people feel that ... if it isn't good for them, they're sort of made to feel like they're doing something wrong" (Katie).

This narrative of CBT effectiveness was also reinforced by some therapists in emphasising to participants the effort required to effect meaningful change through CBT: "you've got to do your bit; you can't just expect, you know, miracles overnight" (Caz). This created an additional pressure during the therapy as participants "started questioning myself" (Caz) as to why CBT was not working for them.

In retrospect, and following subsequent more successful engagement in an alternative therapy approach, one participant, Katie, was able to reconcile this inability to engage in CBT: "looking back I sort of know that actually the failing wasn't with me it was with the therapy." She had subsequently shifted her perception of blame from an internally held belief that she was doing it wrong, to an external rationalisation based on a perception of CBT as limited and inflexible in adapting to individual need and level of engagement.

## Perceived responsibility to therapist.

The perception of self as to blame for CBT ineffectiveness was made additionally complex by several participants' sense of not wanting to upset or disappoint the therapist. For some, this involved "push(ing) myself beyond what I felt comfortable with" (Katie) so as to show willing, or "suggest(ing) that I was doing better than I actually was" (Jimmy). One of the participants had inflated the scores he had reported on a mood scale, so as "to make the counsellor feel better" (Jack) and another had experienced discomfort in providing an honest representation of her mood on the outcome questionnaire:

I felt like I'd be doing her, the person – 'cause we had a really good relationship - almost a disservice for saying 'No, I still feel the same'. I still filled it in honestly but I was thinking I hope you don't see this and think you're doing a crap job, 'cause you're not. (Lisa)

This perceived responsibility for the therapist's feelings compounded existing negative feelings associated with participants' inability to engage and change through CBT: "I felt I was letting myself down, I was letting her down, I was wasting her time" (Luke).

This theme reflects existing research that emphasises individual readiness to engage and change as an important predictor of treatment drop-out and, to a lesser degree, treatment outcome (Dozois, Westra, Collins, Fung & Garry, 2004). Self-efficacy, or an individual's belief in their ability to engage in a therapy intervention and effect change, is also thought to be an important predictor of CBT effectiveness (Gallagher et al., 2013). Perceived self-efficacy could be seen as influential in shaping perceptions of blame and responsibility, as highlighted in the experiences of some participants in this study.

### **Summary of Key Points**

- CBT is not experienced as helpful by all clients with mental health difficulties.
- Primary care services need to consider choice and flexibility of therapy interventions.
- Awareness of the socio-political context of CBT delivery can be a barrier to engagement.
- A collaborative therapeutic alliance is central to clients' positive experiences of CBT.
- Individual readiness to engage and change is an important consideration during the assessment phase and throughout CBT.

### **Conclusion**

Despite CBT being the dominant approach in clinical practice, this study confirms existing research findings that, although associated with improvement across a range of mental and physical health difficulties, CBT is not a panacea. Findings from this study support the crucial role that the therapeutic relationship, individual readiness to change and model-specific factors can have in supporting engagement in CBT.

Additionally, the current study contributes a new understanding of the impact that an individual's preconceptions of CBT and its socio-political context can have on their ability to engage in the model. This is of particular relevance and importance given the current context in western countries of the evidence-based practice movement and the growing preference of healthcare organisations to find psychotherapy approaches that can be standardised and delivered both cost- and resource- effectively.

## **Implications**

Greater consideration needs to be given to how CBT is delivered and by whom. It is apparent from the current findings, that there exists variation between therapists in their approach to CBT delivery. It is imperative that, in keeping with both professional best practice guidelines for health professionals and a more fundamental basis of human compassion, we reconsider the way that primary mental health care services are structured, so that psychotherapy provision is not perceived as a "stick to beat people with," underpinned by a political agenda, but rather permits a collaborative relationship in which individual need, preference and readiness to engage are optimised.

### Limitations

This study represents the views of only a very small sub-set of individuals who have experienced CBT drop-out and thus reflects the views of a particular population. However, the findings do reflect existing quantitative and qualitative research in this area. Several of the participants had accessed CBT in a primary care service prior to the introduction of the government IAPT model in the mid-2000s, and thus may have had a different experience of CBT delivery. Interestingly though, this was not reflected in participants' accounts as there was a shared narrative across the themes, irrespective of the service context in which participants had received CBT.

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CBT DROP OUT EXPERIENCES 2-40

Table 1

Participant Characteristics

Pseudonym	Location	How Recruited	Type & length of Interview	Year & Age Accessed CBT	Previous History or Therapy	Reason for Accessing CBT	Type of CBT and Therapist	Number of Sessions Attended	Reason for Drop Out	Subsequent Therapy Involvement
Becky	London	E-mail to colleagues	Telephone; 23 minutes	2011; early twenties	No previous history or therapy	Anxiety in context of grief and stress	NHS practitioner in primary care service	11	Therapist factors	Bereavement counselling
Caz	Accrington	E-mail to colleagues	Face-to- face; 26 minutes	2014; early forties	Previous history but no therapy	Obsessive Compulsive Disorder	CBT therapist in NHS secondary care service	6	Therapist factors	Pursuing re- referral for CBT
Jack	Manchester	E-mail to colleagues	Telephone; 30 minutes	2012; mid- twenties	No previous history or therapy	Stress	Counsellor in NHS service	3 out of 6	Model factors	Gestalt therapy with private therapist
Jimmy	West Lancashire	E-mail to colleagues	Face-to- face; 22 minutes	2005; early thirties	Previous history but no therapy	Obsessive Compulsive Disorder & depression	CBT therapist in NHS primary care service	4 out of 8	Model factors	Psychodynamic psychotherapy and CBT
Joanne	Lincoln	Online forum	Telephone; 26 minutes	2011-12; mid- twenties	Previous history but no therapy	Anger Relational issues	CBT therapist in NHS primary care service	6 out of 10 then 3	System issues and therapist factors	No subsequent psychotherapy
Katie	Durham	Twitter	Telephone; 41 minutes	2004; early twenties	Yes - previous unspecified therapy	Phobia	CBT therapist in NHS primary care	5 out of 6	Model factors and therapist factors	Person-centred therapy with private therapist

CBT DROP OUT EXPERIENCES 2-41

Pseudonym	Location	How Recruited	Type & length of Interview	Year & Age Accessed CBT	Previous History or Therapy	Reason for Accessing CBT	Type of CBT and Therapist	Number of Sessions Attended	Reason for Drop Out	Subsequent Therapy Involvement
Lisa	Liverpool	E-mail to colleagues	Face-to- face; 35 minutes	2011; mid- twenties	No previous history or therapy	Anxiety	Trainee CBT therapist in NHS primary care service	5 out of 8	Difficulties resolved independently of CBT	No subsequent psychotherapy
Luke	County Durham	Online forum	Telephone; 42 minutes	2010; mid- forties	Previous history & talking therapy	Depression	Occupational therapist in NHS secondary care service	12 out of 24	Model factors	Dialectical Behaviour Therapy skills group
Natalie	Kent	Twitter	Telephone; 44 minutes	2005-12; early-late twenties	Previous University counselling	Stress & Anxiety	Nurse in student services, private counsellor then CBT therapist in NHS service	1 out of 6 3 out of 6 6 out of 12	Therapist and model factors	Mindfulness course and Mindfulness- based therapy
Stockley	York	Twitter	Telephone; 28 minutes	2014; late twenties	Yes, but no previous therapy	Depression	NHS practitioner in primary care service	2	Model factors	No subsequent psychotherapy
Zesty	Durham	Online forum	Telephone; 34 minutes	2014; early thirties	Previous history but no therapy	Depression & disordered eating	Nurse in NHS primary care service	3 out of 6	Therapist factors	Occupational psychology support

### Appendix 2-A

### Participant Recruitment Advert

### PARTICIPANTS WANTED FOR RESEARCH STUDY

Have you had experience of cognitive behaviour therapy (CBT)? Did you choose to drop out of CBT before the agreed timescale?

I am a trainee clinical psychologist based at Lancaster University. I am conducting research into the reasons that adults drop out of CBT and would really like to hear more about your experience. Interviews will be confidential and will not affect any care you currently receive.

If you would be willing to be interviewed (either face-to-face or via telephone) or would like to find out more about the project, please contact **Kay Brewster** (main researcher) via telephone: **07852515788** or e-mail:

k.brewster@lancaster.ac.uk

### Appendix 2-B

### Participant Information Sheet

## The experiences of clients who drop-out of Cognitive Behaviour Therapy (CBT): A qualitative exploration

My name is Kay Brewster and I am conducting this research as a student in the clinical psychology doctorate programme at Lancaster University, Lancaster, United Kingdom.

### What is the study about?

The purpose of this study is to find out more about the individual experiences of adults who choose to drop-out of CBT.

### Why have I been approached?

You have been approached because the study requires information from people who have previously engaged in individual CBT in the community.

### Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

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

If you decide you would like to take part, you will be asked to attend one interview over the next couple of months, which can take place either via telephone or at your home (if you live within 100 miles of Lancaster University), depending on your preference. The interview will last around 30 minutes to one hour, and will be audio recorded. The information you provide in the interview will then be put together with information gathered from other participants and written up into a report which will be submitted as part of my thesis. The thesis will be published and results may also be shared with participants.

### Will my data be confidential?

The information you provide is confidential; your name will not be recorded at interview and any identifying information will be removed from quotes before they are included in the final report. Details of the interview will not be discussed with anyone other than my academic and field supervisors (listed below). If, however, you feel you would like to discuss your involvement in the research with someone you know, that is fine.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

Hard copies of transcripts from the interviews will be kept in a locked cabinet for the duration of the study, then converted to electronic files for storage by the university research coordinator on an area of the university network only they have access to. At this point, hard copies will be destroyed confidentially by the chief investigator

- O Audio files will be stored securely on the university computer system. The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected. These files will not be shared with anyone and will be deleted from the computer system at the end of the research project; once the report has been examined by the University.
- At the end of the project, electronic copies of consent forms, transcripts and the final report will be kept securely on an area of the university network for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to an appropriate member of staff about this. If possible, I will tell you if I have to do this.

### What if I change my mind and want to withdraw my information?

If you decide after the interview that you are no longer happy for your data to be used, just contact Kay Brewster and every effort will be made to remove your data from the final analysis.

### What will happen to the results?

The results will be written up into a report which will be submitted to the university as part of my final year thesis. A summary of the report will be shared with you and other participants. The report will also be presented to some of my colleagues as part of my assessment and may also be submitted for publication in an academic or professional journal and be presented at conferences.

### Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress during or after participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

### Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Findings from the study, however, will help us to present individual client views about CBT and why some people choose to drop out.

### Will I be paid for taking part?

Unfortunately we are not able to provide payment to participants.

### Who has reviewed the project?

This study has been reviewed by the University research ethics committee.

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

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

Main researcher: Kay Brewster

Phone: 07852515788

Email: k.brewster@lancaster.ac.uk

Clinical Psychology,

Division of Health Research,

Lancaster University,

Lancaster. LA1 4YG

**Academic supervisor:** Dr Pete Greasley

Phone: 01524 593535

Email: p.greasley@lancaster.ac.uk

Clinical Psychology,

Division of Health Research,

Furness College,

Lancaster University,

Lancaster.

LA14YG

Field supervisor: Dr Martin Tighe

Phone: 07507856438

Email: Martin.Tighe@lancashirecare.nhs.uk

### **Complaints**

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

Dr Jane Simpson Research Director

Tel: 01524 592858

Email: j.simpson2@lancaster.ac.uk

Division of Clinical Psychology

Furness Building, Lancaster University,

Lancaster. LA1 4YG

Professor Roger Pickup Associate Dean for Research

Tel: 01524 593746

Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine Div. Biomedical & Life Sciences

Lancaster University,

Lancaster. LA1 4YD

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

Professor Bruce Hollingsworth

Head of Division of Health Research

Tel: 01524 594154

e-mail: b.hollingsworth@lancaster.ac.uk

Faculty of Health and Medicine

Furness building Lancaster University Lancaster LA1 4YG

### **Resources in the event of distress**

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

### **Lancashire Care Mental Health Helpline**

Freephone: 0500 639 000

Open Monday – Friday 7pm – 11pm, Saturday and Sunday 12 midday to 12 midnight Free information and listening service

### **Cumbria Partnership Direct**

Telephone: 0800 171 2333

24-hour helpline for residents of Cumbria with mental health problems.

### **Cumbria Health on Call (ChoC)**

Telephone: 03000 247 247

Open Monday to Friday 6.30pm until 8.00am 24 hours

throughout the weekend

24 hour cover on Bank Holidays including Easter, Christmas and New Year. For urgent out-of-hours GP contact and referral to urgent mental health services

### **Samaritans**

Phone: 08457 90 90 90 E-mail: jo@samaritans.org

24 hour confidential emotional support service via telephone, e-mail or face-to-face contact

Thank you for taking the time to read this information sheet

### Appendix 2-C

### Participant Consent Form

Study Title: The experiences of clients who drop-out of Cognitive Behaviour Therapy (CBT): A qualitative exploration

We are asking if you would like to take part in a research project exploring the experiences of adults who drop out of CBT in the community.

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

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

Name of Participant:
Signature:
Date:
Name of Researcher:
Signature:
Date:

### Appendix 2-D

### Descriptive Biography of Each Participant

### **Becky**

Becky lived in London and was recruited via social media. She had accessed CBT within an NHS primary care service when in her early twenties, for support with anxiety in the context of bereavement and life pressures. Becky had no previous therapy experience and no history of mental health difficulties. She had attended 11 sessions and then had dropped out, mainly due to therapist factors as she had found the CBT techniques useful, although limited. Becky had subsequently engaged with bereavement counselling several years later, following a separate bereavement, and had found this approach more helpful (although had also continued to use some of the CBT skills).

### Caz

Caz lived in Accrington and was recruited via the e-mail to colleagues. She had accessed CBT with a CBT therapist in an NHS secondary care service when in her early forties, for support with difficulties associated with a diagnosis of obsessive compulsive disorder. Caz had no previous therapy experience, but had a history of mental health difficulties. She had attended six sessions then had been advised by the therapist that CBT was not working, despite Caz perceiving CBT as helpful. Caz had subsequently sought CBT with an alternative therapist.

### Jack

Jack lived in Manchester and was recruited via social media. He had experienced CBT with a counsellor when in his mid-twenties, for support in managing increased life pressures. Jack had no previous therapy experience or history of mental health difficulties. Jack had attended three out of six planned sessions and then had

dropped out as he felt that the CBT approach had not been helpful, due to factors associated with both the model and therapist. Jack had subsequently engaged in Gestalt therapy with a private therapist, which he had experienced as more helpful.

### **Jimmy**

Jimmy lived in West Lancashire and was recruited via the e-mail to colleagues. He had accessed CBT with a CBT therapist in an NHS primary care service when in his early thirties, for support with OCD and low mood. Jimmy had no previous therapy experience, but had a history of mental health difficulties. Jimmy dropped out after approximately four of the eight planned sessions as he felt that the CBT model was not helpful. He had subsequently engaged in psychotherapy and (more structured) CBT with a different therapist, which he had experienced as more helpful.

### Joanne

Joanne lived in Lincoln and was recruited via an online support forum. She had accessed CBT with a CBT therapist in an NHS primary care service on two separate occasions, when in her mid-twenties, for support in managing anger and with relationships. Joanne had no previous therapy experience, but had a history of mental health difficulties and medication use. With the first CBT, Joanne attended six out of ten sessions, then missed one and was not allowed to continue (but had found CBT helpful). With the second CBT, Joanne had attended three sessions, then again missed one and was not permitted to continue (however, had not found CBT as helpful due to therapist factors). Joanne had not engaged in any subsequent therapy due to a loss of trust in the therapy process and system.

### Katie

Katie lived in Durham and was recruited via social media. She had experienced

CBT with a CBT therapist (Psychiatrist) when in her early twenties, for support in managing a phobia. Katie had previous experience of unspecified psychological therapy and had a history of mental health difficulties. Katie had attended five out of six planned sessions and then had dropped out as she felt that the CBT approach had not been helpful, due to factors associated with both the model and therapist. Katie had subsequently engaged in person-centred therapy with a private therapist, which she had experienced as more helpful.

### Lisa

Lisa lived in Liverpool and was recruited via social media. She had engaged in CBT with a trainee CBT therapist in an NHS primary care service, when in her midtwenties, for support in managing situation-specific anxiety. Lisa had no previous therapy experience and no history of mental health difficulties. Lisa had attended five out of eight planned sessions, and had then dropped out as her difficulties had resolved independently of therapy. Lisa had not engaged in any subsequent therapy as this had not been necessary.

### Luke

Luke lived in County Durham and was recruited via social media. He had accessed CBT with an occupational therapist trained in CBT, within an NHS secondary care service, when in his mid-forties, for support with low mood. Luke had previous experience of talking therapy with a clinical psychologist and had a history of mental health difficulties. He attended weekly sessions for three months (halfway through the planned timescale), and then dropped out as he had not found the CBT model helpful. Luke had subsequently pursued a referral for more in-depth therapy for support with

past trauma and had also attended a dialectical behaviour therapy skills group, which he had experienced as helpful.

### **Natalie**

Natalie lived in Kent and was recruited via social media. She had accessed CBT on three separate occasions, when in her early, mid, then late twenties. The first CBT was with a mental health nurse through University student services, for support with stress. Natalie had dropped out during the first session due to therapist factors. The second CBT was with a private counsellor, for support with anxiety in the context of past trauma. Natalie had attended three out of six planned sessions, then dropped out as she felt unable to engage due to persistent high levels of anxiety (the therapist had also suggested that CBT was not working). Natalie's third experience of CBT was with an NHS-commissioned CBT therapist, again for support with anxiety in the context of past trauma. Natalie had attended six out of twelve sessions, and then felt that she was able to cope independently of CBT. Natalie had engaged in previous counselling whilst at University and had a history of mental health difficulties. She subsequently engaged in a mindfulness course and in mindfulness-informed therapy with two different therapists, which she found more helpful as a model.

### Stockley

Stockley lived in York and was recruited via social media. He had experienced CBT with an NHS practitioner as part of a primary care service when in his late twenties, for support in managing low mood. Stockley had no previous therapy experience but had a history of mental health difficulties and medication use. Stockley had dropped out after the initial two sessions as he had felt that the CBT approach was

not helpful as a model. Stockley had not engaged in any subsequent therapy, based on his negative experience of CBT.

### **Zesty**

Zesty lived in Durham and was recruited via an online support network. She had accessed CBT with a mental health nurse in an NHS primary care service when in her early thirties, for support with low mood and disordered eating. Zesty had an extensive history of mental health difficulties and had engaged in several previous therapies (private and NHS) but had no prior experience of CBT. She had attended three out of six planned sessions then dropped out as she had not found the CBT helpful (mainly due to therapist factors). Zesty subsequently sought support via an occupational psychologist and found the practical approach more helpful, but would still consider CBT.

### Appendix 2-E

### Interview Topic Guide

### PART A. Descriptive Information

- Age when attended CBT: 18-24, 25-34, 35-44, 45-54, 55-64, 65+
- Gender
- Type of CBT accessed and qualification of CBT therapist
- Approximate date CBT started and ended
- Details of any other previous therapy experience

NB. The following questions will be used as indicative prompts with which to guide the interview structure; however participants will also be encouraged to elaborate on other issues that they raise and which are relevant to the research topic.

Can you tell me about the reasons you had for accessing CBT?

- How were you referred?
- What qualification did your therapist have?
- Did you have a choice of therapy?

### What format did the CBT take?

- How many sessions and how often?
- What did you do in the sessions?
- Was there any 'homework' outside of the sessions?

### How did you get on with the therapist?

- Were there any disagreements and how were these resolved?
- How involved did you feel in the therapy process?
- How were goals and timescales agreed?

What led you to drop out of therapy?

- When did this happen?
- How did you decide?
- How did you do this?

What effect did dropping out have on you?

- Did you seek support from an alternative source?
- Did it change your opinion of therapy more generally?
- Would you act differently if in the same position now?

### Appendix 2-F

### Excerpt of Coded Transcript

54	were you referred for that? Did you self-refer or was it through your	
55	GP or another way?	
56	Yeah, I'm just trying to think back- I think it was after- oh yeah erm I	Again, unclear on
57	had an assessment with a clinical psychologist, actually I don't know if	profession/role
58	she was a clinical psychologist but she was a psychologist	T
59	OK	Impact of previous experience on
60	Erm and ermm she ermm- she offered me the alternative by- I had the	decision to have CBT
61	choice of seeing a clinical psychologist or CBT and because of my	Assumption that
62	previous experience with a clinical psychologist I chose the CBT	clinical psychology
63	Mhm	different to CBT
64	But erm my parents- my father came with me at first and erm- there	
65	was-there was my emetophobia and also I had a lot of obsessive OCD,	Father attended
66	like quite a few compulsive behaviours	session
67	OK .	
68	And erm my parents wanted me to work on the compulsive behaviours	Own choice for focus of therapy; chose
69	but I chose the emetophobia because of my anxiety around erm-	differently to what
70	around vomiting because I had to- I was planning a gender	parents wanted
71	reassignment	parents wanted
72	Mhm	CBT did not allow
73	And ermm, but it was focussed-the CBT wasn't looking at why I had	for context
74	the issues I did or- I find talking about things a lot more helpful, but	
75	the therapist said that isn't what we're here to do, we're here to sort of-	CBT as a practical
76	do things and sort of challenge the phobias and I found it was very- it	'succeed or fail'
77	was a bit too succeed or fail	approach
78	OK	Perceived as a battle
79	And erm	Terceived as a battle
80	So how many sessions did you attend?	
81	Ermm I think it was probably erm- I think it was probably about 5	CBT a struggle
82	approximately, I can't be sure, ermm but uh- I- I did find myself	
83	struggling erm I- I'd probably be able to tell you more if I thought	
84	about it cause I do have- erm I'm known for having a very good	
85	memory even for things a very long time ago but that- that number of	
86	times could be inaccurate	
87	OK, and do you know how many sessions-had you agreed a number	
88	of sessions at the beginning that you would be spending on it with the	
89	therapist or were you just seeing how it went after each?	Prior knowledge and
90	I think they usually say 6 sessions but I don't know- I think there	expectation of what
91	weren't that many, I know there weren't that many but erm yeah there	CBT would involve
	2	

Use of irrelevant

metaphor by

therapist

126

127

128

129

actually play tennis, so-

weren't that many sessions but erm- uh yeah I sort of struggled a lot 93 and erm- and I think that I erm used to feel bad because I couldn't- I Feeling badbecause unable to 'do' CBT 94 couldn't do it. I couldn't do what the therapy was asking CBT challenging 95 OK and can you think - did you think then or since why that might Different perspective have been, that you struggled to do what was being asked? now looking back 97 Yeah, well looking back I mean at the time things were a lot harder but Fault not me but the 98 looking back I sort of know that actually the failing wasn't with me it therapy 99 was with the therapy 100 Mhm CBT limited, does 101 And I felt very restricted and I have a lot of issues with security and not consider 'why' 102 abusive childhood but I think with CBT I found that they're-they're not looking at the sort of why it happens or- or like I felt that I was CBT about 103 symptoms not causes 104 ticking their symptoms that's all 105 OK and were you able to have a conversation about that with the Push beyond comfort 106 therapist or did you feel that you just had to get on with it? level so as not to 107 Yeah well I- I didn't feel able to erm- I did feel, I did push myself upset therapist 108 beyond what I felt comfortable with cause I think I was worried about Impact of previous 109 erm- about upsetting the therapist or erm- or like erm, cause I sort of bad experiences of felt I'd had quite a few bad experiences with erm the health 110 health professionals 111 professionals in general and I think that this belief that they're the and view of their role 112 therapist you're the patient and they're trying to help you, so I did feel as expert therapist Blamed self for not 113 erm- I did feel that erm - so I guess I did feel that I was supposed totrying hard enough 114 that I sort of wasn't trying hard enough or things like that 115 OK. And how did you feel you got on with the therapist kind of Therapist as difficult 116 personally, like more generally than the actual CBT skills side of it? to talk to and Erm I think I erm- yeah I felt I just couldn't talk to him about anything 117 perceived as and felt the therapist wasn't interested in erm- in what I had to say 118 uninterested 119 And was there anything in particular that they did to cause you to feel 120 that way Blaming, 121 I think sort of when I said what uh- what my- uh- what my difficulty judgemental 122 with it was I think he was saying sort of things like oh you just need to language from 123 push yourself erm a bit more and things like that and uh I remember therapist Challenge of CBT him saying that you need to push yourself as if erm as if you're 124 125 playing a game of tennis I remember him saying that

OK and was tennis something that he was using because you're keen

No it's just it's something he said and I remember thinking well I don't

on tennis, or was that one of his own kind of analogies?

### Appendix 2-G

### Example of Theme Development

THEME ONE: Socio-political context	SUPPORTING QUOTES
Surprise at short waiting time	it
Benefit of not having to wait for CBT	just sort of seems to be erm something that's preferred from a business point of view (Jack, 269-271)
Prior knowledge of CBT and IAPT	I think the service, yeah I think that's just generally what everybody got (Jack, 117-118)
CBT as diagnosis-dependent	
Systemic context of CBT	he was off sick a lot so it never got implemented they mislaid my referral for like well over
Political context of CBT	a year (Katie, 314/5 & 324/5)
CBT as helpful for some people at some times; not a panacea	different things might work for different people and I think erm listening to what works for the person is important
Awareness of political context of CBT and government agenda influenced preconceptions of how useful CBT would be	(Katie, 426-427)
CBT or nothing: if ineffective, left to cope alone	I'm perhaps aware of erm the political context of CBT being used by the government as kind of a stick to beat people with, so you will do CBT or you will potentially
CBT seen as a supplement to medication	lose your benefits or you know, if you don't accept CBT or you decide not to do CBT then you're not doing everything you can to get better
CBT as only option	(Stockley, 112-116)
Systemic issues around difficulty in accessing alternative forms of therapy through NHS	it would have been nice to feel that I wasn't just sort of being well you've tried this and now
Government agenda around mental health treatment	you're back to being on your own with the illness (Stockley, 181-183)
CBT preferred model by government as quantifiable	the difficulties or at least perceived difficulties for me of getting other kinds of therapy through the NHS er rather than doing
CBT as vehicle for government to get people off benefits and back to work	it privately, erm that is still a significant barrier to me seeking other forms of therapy (Stockley, 221-224)
Government holds responsibility and blame with individual if CBT ineffective	merupy (Grockley, 221-227)

CBT DROP OUT EXPERIENCES 2-60

CBT viewed as an ideological, rather than evidence-based approach

Political context of budget cuts influencing waiting times

Mental illness as invisible and thus neglected by government

Waiting times for therapy send message that individual is unimportant time waster

Length of wait would influence choice of therapy

Waiting list as part of political agenda to place blame on individual

Impact of staff absences (the system) on treatment received

Dynamic nature of mental health as influencing therapy needs and goals

Negative impact of system and procedure on ability to access therapy

Having to advocate needs in order to have choice in therapy

Seeking support from a private therapist in order to get needs met

Able to make an informed choice over (private) therapist

Impact of societal belief that CBT is effective can cause individuals to feel that they are doing it wrong if not effective

Positive impact of knowing that others also struggle to engage in CBT

Alternative approaches, not one size fits all – what works for whom

Ability to draw on range of support resources in managing difficulties

Political context of CBT as a good business model of therapy

CBT as a quick and cheap alternative to longer, preferable alternatives

System limitations of CBT; rigid boundaries around missed sessions

... the reason why the government

latched onto CBT as erm the be all and end all of you know treatment erm is partly that it's quantifiable, that you can- there's quite a lot of data out about it (Stockley, 230-233)

... CBT has these kinds

of- this number of sessions and the x percentage of people who are treated with CBT or CBT in some association with er medication get better or are able to go back to work, which is what they really care about, I suppose. Erm and the idea of CBT then- therefore can be used as some kind of stick to beat people on disability benefits, you know if you are depressed, if you are suffering from any other kind of mental illness, CBT is the cure that is- that we say works for everyone, even though it clearly doesn't, yet we as the government can say it works- we've shown it works, we've found a cure, if you refuse to be treated in this way or if you don't get any better from this kind of treatment then that is you- that is absolutely your problem, being too stubborn to get better and therefore we have a erm excuse to take you off your er benefits or we have an excuse to say er it's not that you are unable to work, you are choosing not to work and to me that's utterly abhorrent and terrifying, horrifying (Stockley, 235-249)

... I think the idea that (sighs) the government thinks it's acceptable to just slash treatment for mental health er- well slash funding for mental health treatments erm because in some way they are less- perhaps in their minds they are less obviously serious, they're less visible maybe? (Stockley, 280-284)

... I can imagine I got the CBT because of that- that diagnosis on piece of paper, based on those scores I answered on that first assessment (Lisa, 356-358)

...I appreciate that's how the system works, but it shouldn't (Lisa, 380)

... that's the way it's set up and I know why it's about money and like reaching thresholds and stuff (Lisa, 393-394)

... I didn't realise that even in- you know it was an extenuating circumstance I hadn't done it intentionally, that that would be the case and I didn't realise it was a **no-strike rule (Joanne, 115-117)** 

CBT DROP OUT EXPERIENCES 2-61

Socio-political context of CBT

Systemic context of NHS as affecting therapy and demands on therapist

Therapist and system experienced as dismissive

Subsequent reliance on online support network

Transparency of communication with online support group

Long waiting list

Therapist as inflexible and representative of wider system

Long wait for CBT influenced expectations of CBT effectiveness

The system

Longer duration for CBT

Reluctance to drop out of CBT until substitute therapy offered: something better than nothing

I know Lincolnshire is probably the least funded county in the country and basically we probably get the worst medical NHS treatment in the country because we have no funding (Joanne, 124-126)

... the rules have changed to get a CPN, it's not as easy as it used to be. (Caz, 108-109)

... when you

arrived, you had to fill in some kind of mood questionnaires and anxiety questionnaires and like how much time have you had off work in the last week or whatever and erm it was presumably all about measuring their effectiveness (Natalie, 277-281)

... they weren't sure that I wanted to go erm that they wanted to sort of send me straight back to secondary services cause it didn't seem quite appropriate so that's how I ended up with the CBT therapist (Zesty, 43-46)

... there was often three questionnaires, it felt a bit excessive

but I knew that obviously that was part of the study, not everyone would have to do that (Becky, 81-83)

... for a few years I- I didn't want to go back to services because I felt that maybe they'd all be the same (Becky, 204-205)

... It sounded like a good stint to me, 'cause I'd read about sort of 8 or 12 weeks stints of CBT (Luke, 107-108)

Not until she said she could refer me somewhere else, I was desperate for something, I was desperate for some sort of therapy, some sort of involvement from services erm and- and I wouldn't really let go of CBT (Luke, 219-222)

the questionnaires weren't even

in the session, cause they were just given out in the waiting room (Zesty, 339-340)

### Appendix 2-H

Author Guidelines for Submission to Clinical Psychology & Psychotherapy-journal

### Clinical Psychology & Psychotherapy

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Section Three: Thesis Critical Appraisal

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### Thesis Critical Appraisal

Findings from the meta-synthesis and research paper generally indicate that CBT can be experienced as beneficial by some individuals in the context of chronic physical and/or mental health difficulties; however barriers to positive engagement exist in relation to factors associated with the CBT model, therapeutic alliance and broader socio-political context.

The aim of this review is to reflect on key aspects of the research process, with reference to strengths and limitations and suggested areas for further research. A theme that I have encountered throughout the project has been a growing awareness and consideration of the impact of occupying the position of both clinician and researcher, and the dual impact of this as a two-way process. Therefore, I have chosen to largely structure the following review in two parts: The impact of my clinical role as a trainee clinical psychologist on the research process and the impact of the research process on my clinical role. Following consideration of these two areas, I will also discuss general challenges I encountered whilst conducting this study; strengths and limitations; and suggestions for future research.

### Impact of my Clinical Role on the Research Process

My initial interest in this area came from my background of working in a range of NHS and private clinical settings and becoming increasingly aware of the agenda at service-level and nationally to provide evidence for therapy effectiveness. This growing emphasis on evidence based practice corresponded with the 'Payment by Results' (Department of Health, 2012) government initiative in England, by which healthcare providers are now commissioned to provide targeted care in accordance with nationally determined currencies and tariffs based on clusters of need. I had encountered this at

different levels depending on the service, in relation to the impact that this agenda had on subsequent decision-making about available models of treatment and timescales for therapy. I had also experienced differing approaches in my clinical supervisors over the course of training: whereas some appeared to embrace the inherent boundaries and structure that an evidence-based practice model conferred, others were critical of this seemingly reductionist approach to the conceptualisation of mental health difficulties. These influences, in addition to encouragement as part of the clinical psychology training programme to engage critically with current practices, led me to develop the current project idea.

Based on my awareness of the above, I was mindful from the start of the project that there was a likelihood that my views could influence the project design; both as a practising clinician of CBT and other models and in the current climate of a changing NHS, in which objective measurement in therapy is becoming increasingly prominent. Research within a quantitative context has indicated that a therapist's own belief in and allegiance to a therapy model can have an impact on the research process and outcome (Messer & Wampold, 2002). Similarly, in conducting the empirical study I was aware of the potential impact of sharing my rationale and interest in the topic area with participants. Conducting the literature review before the empirical paper helped me to remain balanced about CBT, as the focus of the meta-synthesis was on the positive experiences of people who had found it helpful.

My epistemological position as oriented towards social constructionism also influenced my engagement in the research process for the current study. Braun and Clarke (2006) highlight the different theoretical frameworks (realist, constructionist or contextualist) that can inform thematic analysis. I employed a contextualist method,

informed by critical realism, in order to "acknowledge the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of reality" (p.81). I place a relatively strong emphasis on the role of socio-political influences in shaping an individual's experience and identity. As such, I do not fully support the diagnostic criteria employed by mental health services as a means for determining an individual's difficulties and needs; however I also recognise that, for some individuals, diagnosis can facilitate meaning-making of a difficult experience. I was thus mindful of not wanting to impose my views on participants as part of the research process and of seeking to prioritise their individual experiences in the analysis.

One issue that arose during the research interviews was the sense of professional responsibility I experienced when hearing some participants' negative narratives of the service limitations that had led to their CBT drop-out. Policies within some primary care services, such as the stipulation that individuals must attend all scheduled sessions, appeared to contradict the inclusive, flexible approach that, as clinical psychologists, is an integral aspect of our role. The British Psychological Society, in their code of ethics and conduct (2009), specify that psychologists should make clear to clients at the earliest opportunity the conditions under which their services may be terminated and, in the case that they are, should refer clients to alternative sources of support. The experience of at least one participant suggested that this had not been achieved.

I experienced conflict in feeling that I wanted to do something to make the situation and difficult experience better, particularly with participants who had experienced CBT or the service as so limiting that they had not sought further therapeutic support, despite experiencing ongoing mental health difficulties. Research

has suggested that there are commonalities between the researcher-participant relationship and the therapeutic relationship (Hart & Crawford-Wright, 1999), with the fundamental difference that in research, the participant is primarily helping the researcher, whereas in therapy this is reversed. With the current study, both of these dynamics felt salient: the participants were helping me by sharing their experiences; however I also felt with some that I was helping by offering an opportunity to be heard and obtain closure on their difficult experience of therapy. When conducting the project, I was aware of the importance of wanting to offer feedback and recognition of participants' involvement, which I achieved by offering to send each participant a summary of the research findings once completed. Many appeared surprised at this offer, which perhaps reflected an assumption of professionals or services 'taking from' or 'doing to' and not offering anything in return.

This led me to reflect on the motivation of participants to engage in the current project despite, or perhaps because of, their negative experiences. Some participants had reported that they had felt an obligation to support the research as they were or had been researchers themselves, whereas with some participants there was a sense that they had taken part as a means of getting their experience heard by somebody (me) who may be in a position to influence the way future services are delivered. Interestingly, despite their awareness of my role as a trainee clinical psychologist, only two of the participants appeared to make any assumptions about my role and/or knowledge of CBT and service delivery, suggesting that they perceived my role as a researcher as separate and distinct. One of these participants, following the interview, asked whether I would mind answering some questions about clinical psychology doctorate training, which again

decreased my identification as a clinician; the boundary shifted to a more natural interaction, distinct from the research process.

In designing the project, I had attempted to be as inclusive as possible with the recruitment strategy, in not limiting participants based on demographic information or their background experiences and in using several means of recruitment to try to reach as broad a population as possible. I used Twitter as it represents an open community and is used by many as a professional and/or personal forum for highlighting and exploring sensitive or controversial issues. Setting up a dedicated Twitter account for the project meant that I could limit activity to project-relevant information; however this method of recruitment raised several challenges. Prior to the project, I had only a limited working knowledge of Twitter, so did not know the most appropriate way to use it as a vehicle for recruitment. The restriction on word count made it difficult to convey key information about the project whilst also attempting to sound approachable. I also experienced difficulty in approaching the organisations to support recruitment on Twitter, as there were different methods for this. These difficulties placed me in the uncomfortable position of inexperienced and unknowing, and caused me to reflect on the potential similarities of experience shared by participants accessing a new service and therapy for the first time.

Another consideration with using Twitter was the immediacy with which contact can be made and my attempt to balance appropriately timely responses so as to keep momentum and interest from potential participants with a professional boundary in not responding to messages during antisocial hours. I also became more aware of the use of Twitter as a political platform and the potential influence of this in relation to the characteristics of participants in the current study as perhaps motivated by their own

agenda, particularly in the context of their level of awareness of socio-political influences on CBT delivery.

The ability of participants to remain visually anonymous in the research was another consideration. In my attempt to be inclusive, I was aware that for some individuals, a requirement to meet face-to-face may represent a barrier to their engagement in the interview process. This was apparent in the preference of several of the participants to conduct the interview via telephone, irrespective of geographical considerations. One of the participants also spoke about her current experience of an alternative form of therapy that is delivered via telephone in order to accommodate her inability to leave the house. There has been a recent increase in the development of alternative forms of therapy, such as computerised CBT, driven primarily by a need for greater cost- and resource- effectiveness in mental health services. Research into these methods has indicated mixed experiences in comparison to face-to-face therapy (Knowles et al., 2014) with service users reporting either a heightened sense of empowerment and mastery as a result of achieving positive change through computerised CBT or finding the experience burdensome, inflexible and isolating.

### Impact of the Research Process on my Clinical Role

Reviewing the literature on different factors influencing CBT delivery led me to develop a greater awareness of the individual differences between therapists and also the apparent difference in standards of training amongst staff delivering CBT. This was also highlighted in the experiences of participants I interviewed, as reflected in the subtheme of therapist competence.

In a recent qualitative study, Muse and McManus (2015) explored the concept of therapist competence in CBT, by interviewing 19 'experts' on their views of what CBT

competence represents. Factors such as flexibility in selection and delivery of interventions and in the interpersonal style of the therapist were suggested as representative of competence. Participants also questioned whether a protocol specific approach was necessary or realistic outside a research context and highlighted how, for trainee CBT therapists, therapist rating scales can become 'box-ticking exercises,' whereby trainees focus on achieving high ratings rather than on delivering high quality CBT. Additionally, participants reflected on the outcome measures used in CBT as not necessarily an indicative measure of CBT therapist competence.

Increasingly, professionals other than psychologists and therapists are expected to deliver CBT for both physical and mental health difficulties. As part of my current and previous placements in physical and mental healthcare settings, a key aspect of my role has been to assist in delivering training on CBT techniques to nursing and medical staff members. Crawford, Brown, Anthony and Hicks (2002) highlight the challenges experienced by community mental health nurses in attempting to adhere to an evidencebased practice model of service delivery. Findings based on interview and focus group data indicate several influential factors, including the inaccessibility of published research in clinical settings, a prioritising of clinical experience and working knowledge in comparison to research findings and organisational constraints such as time and resource pressures. Similarly, Aschim, Lundevall, Martinsen and Frich (2011) conducted a qualitative exploration of GP experiences of delivering CBT. They found that factors increasing the ease of CBT delivery included structured supervision and group counselling and a sense of mastery, whereas factors that limited GP's ability to deliver CBT included time constraints and a lack of financial incentive. Research has also shown that non-psychologist professionals can lack confidence in delivering

therapy (e.g. Donoghue et al, 2004), which further emphasises the need for adequate training and supervision.

Another issue that arose as a consequence of the research process was participants' narratives around aspects of the therapeutic process that they had found particularly helpful or unhelpful, leading me to consider my own clinical practice and whether I engage in any of these. A particular focus for this was on the positive account by several participants of appropriate therapist self-disclosure. Goldfried, Burckell and Eubanks-Carter (2003) highlight the benefit of therapist self-disclosure in CBT, in strengthening the therapeutic relationship and in normalising aspects of an individual's experience. Based on a history of working in secure forensic settings, I had previously avoided any form of self-disclosure in therapy; however I have noticed that as a result of the research I have started to offer more personalised examples or details, in the context of therapy, with positive results.

As part of the literature search for the empirical paper, I encountered research which indicated that, for some people, psychotherapy can be harmful (e.g. Barlow, 2010; Castonguay, Boswell, Constantino, Goldfried & Hill. 2010). Interest in this concept led me to read Bates' (2006) book on experiences of clients who have found therapy unhelpful, or even detrimental. I was also made aware through a University teaching session of the 'Supporting Safe Therapy' website (http://www.supportingsafetherapy.org/) that has recently been created as part of a larger project exploring client negative experiences of psychotherapy. Increased awareness of the potential for harm in therapy further reinforced my critical views on the structure of CBT delivery in many primary mental healthcare services in the UK.

I was surprised at the level of awareness that several participants had of the socio-political context of CBT delivery. This caused me to reflect on the broader expectations and preconceptions that a client may bring to an initial therapy assessment, and the potential impact that this may have on their ability to engage. The additional issues raised by participants in relation to outcome measurement in CBT also highlight a bigger issue with the way evidence-based services are delivered. As psychology professionals, there is feasibly some tension in supporting a 'common factors' model (e.g. Luborsky et al., 2002) by which there is parity of outcome across different therapy models and where therapist factors are seen as having the greatest influence, whilst also advocating the use of CBT as a panacea for an ever-increasing range of physical and mental health difficulties.

The preference of several participants to be interviewed via telephone, rather than face-to-face, increased my awareness of the various difficulties that many individuals have in attending face-to-face appointments. I have experienced a greater degree of flexibility in physical health psychology services than mental health services in relation to offering alternative formats for therapy delivery; such as home visits, telephone or e-mail consultations. This again reflects a wider issue around the difference in social expectations and stigma around physical or visible difficulties, in comparison to psychological or unseen health difficulties. This social difference was highlighted in the background literature I read around chronic conditions and the relative difference in social support and acceptance associated with visible versus unseen illness. In her book on work and unseen chronic illness, Vickers (2002) highlights the 'fallacy of wellness', by which the absence of visible signs of illness leads others to assume that an individual is well and healthy and thus neglect to provide

appropriate support and recognition of difficulty. Vickers specifically highlights the detrimental role of employers and workplace organisations in marginalising individuals who have a chronic health condition, based on a societal view of health as a commodity in Western countries. This could be seen as inherent in the apparent discrepancy between the socio-political agenda of employability as an expectation of engagement in CBT for a mental health difficulty, compared to improved quality of life as an aim of engagement in CBT for a chronic illness such as cancer.

# **Challenges in the Research Process**

When attempting to identify a research question for the meta-synthesis, I encountered difficulty in searching for and locating relevant papers on the topic of service user experiences of CBT in a physical health context. The varying terminology used in relation to qualitative research design, CBT and chronic health conditions created a barrier to readily identifying relevant papers. This perhaps reflects a broader issue around the accessibility of research, particularly qualitative, to inform evidence-based practice and also highlights the complex terminology used in both physical and mental health services, which may feasibly create a barrier to both professionals and service users.

During the initial recruitment phase I experienced some difficulty in obtaining permission from support organisations to recruit via their forums or support centres. Although some described a conflict of interest for their service, presumably in the context of the government-level agenda of CBT delivery, some reported that they were unable to support recruitment due to the potential vulnerability of service users. This appeared to be a somewhat conflictual approach, in encouraging service users to share difficult experiences on a minimally-controlled online forum, whilst also denying them

the opportunity to share their experiences at a more public level in the context of an ethically-supported research study.

Another challenge I faced was adhering to the inclusion/exclusion criteria when recruiting participants to the research project. In response to the recruitment advert I received two messages from individuals who had not dropped out of CBT, but who had only engaged in the full course of therapy in order to be eligible for an alternative therapeutic approach. Despite stipulating that I would not be able to include them in the study, one of the individuals subsequently e-mailed me a description of their experience of services and I experienced a dilemma in that I did not want to appear dismissive of their experience, which had been challenging; however I was not able to include their account in the current project. Similarly, in response to the information I placed on Twitter, I received an e-mail from a Solution-Focussed therapist. He expressed interest in the project and had circulated the research question to therapist colleagues, who had subsequently provided written responses of their experiences of client drop-out from CBT (prior to engagement in solution-focussed therapy). Interestingly, factors associated with CBT drop-out, based on these responses, fit within the three categories identified in the current study:

- 1) Therapist factors: Not being listened to, feeling 'done to' or perceiving the therapist as a 'joke.'
- Model factors: CBT perceived as inflexible and rigid, due to the training process for many primary care practitioners as limited to a manualised format of CBT delivery.
- 3) Socio-political context: Limited choice in therapy and limited flexibility in therapy delivery in relation to length and spacing of sessions. Also, limitations

associated with outcome measurement as focussed on problem reduction and skills development in order to manage life issues better, rather than a more individualised consideration.

Although unable to directly use this information in the current study, the level of interest was indicative of a broader critique of CBT by representatives of other therapeutic modalities.

# **Strengths and Limitations**

A key strength of the project was the inclusive approach taken to recruitment, in not limiting participants by nature of the CBT they had received and in not restricting participation based on location, age or reason for accessing therapy. Use of social media and word of mouth approaches also supported a broad recruitment strategy.

The qualitative design permitted an in-depth exploration of individual experiences of CBT drop-out and, although the findings can only be seen as representing the individual views of a small sub-set of individuals, from within the UK, the similarity of experience between individual participants suggests that there are common influences on the phenomenon of CBT drop-out.

### **Further Directions for Research in This Area**

Further research is indicated to explore the challenges and facilitative processes that are faced by non-psychology professionals delivering CBT in the community. This will inform clinical psychologists' understanding of our role in delivering training and supervision to colleagues.

Additionally, further qualitative research on the experiences of both therapists and service users on CBT and alternative therapy approaches will advance our understanding of the factors influencing motivation, engagement and therapy drop-out.

Specific areas for research focus could include an exploration of the impact of awareness of socio-political context on psychotherapy engagement and the nature of the role of therapist self-disclosure in facilitating engagement.

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Section Four: Ethics Documentation

# Kay Brewster

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

# **FHMREC Approval Letter**



Applicant: Kay Brewster Supervisor: Dr Pete Greasley

Department: DHR

05 January 2015

Dear Kay and Pete,

Re: The Experiences of clients who prematurely disengage from Cognitive Behavioural Therapy (CBT): A qualitative exploration

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

As principal investigator your responsibilities include:

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

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 <a href="mailto:ethics@lancaster.ac.uk">ethics@lancaster.ac.uk</a>) if you have any queries or require further information.

Yours sincerely,

S.C. Tange

Sarah Taylor Secretary, University Research Ethics Committee

Lancaster University

Cc Fiona Aiken, University Secretary, (Chair, UREC); Professor Roger Pickup (Chair, FHMREC)

Lancaster University Bowland Main Lancaster, LA1 4YT, UK T: +44 (0)1524 592 002 F: +44 (0)1524 593 229 www.lancaster.ac.uk

### **FHMREC Review Feedback Letter**



#### **Faculty of Health and Medicine Research Ethics Committee**

Our ref: FHMREC14020

20 November 2014

Kay Brewster Division of Health Research Faculty of Health and Medicine Lancaster University

Dear Kay

Re: FHM Research Ethics Committee application for project titled: 'The experiences of clients who drop out of Cognitive Behavioural Therapy (CBT): a qualitative exploration'.

Thank you for sending in the paperwork for your application. We appreciated reading about the project. We have a few minor concerns, and ask that you address the following in revising your application materials:

#### General

 Please use the correct Faculty logo (included at the end of the email in which this letter was sent).

## Application section 10

 add a sentence noting that you are only interested in the experience of people who opted for community based individual face to face CBT. You have excluded telephone or self-directed CBT.

### Application section 10

o Amend the start date to take into account the timescale for ethical approval.

#### Application section 12

 People who have accessed and then withdrawn from CBT may have mental health issues which require you to consider matters of safeguarding: explain in more detail about how you will decide they are well enough to take part in your study

### Application section 13

- The committee asks that you do not use Facebook, since Facebook rules mean that you can only use your own page and this is not a safe option for you.
   However, you may wish to consider Twitter as an alternative, as this enables you to set up a professional account which participants cannot trace back to you.
- You may also wish to recruit via relevant chat forums, ensuring that you get approval from the site admin before going down this route. If this approach is used, and requires additional recruitment materials, these should be submitted as an amendment request.

#### Application section 14

- o Clarify in this section whether you will provide a SAE for a posted form?
- Where the consent form is to be sent by email, give details of how will this be handled if the participant does not have access to a printer. We suggest it would be best to only provide hard copies.

#### Application section 15

 Those who have accessed and withdrawn from CBT may well have issues which cause them distress, and which are triggered by taking part in the study, even where this is not caused by the study questions, So acknowledge this more clearly in this section.

#### Application section 19

- o State where in the University you intend to carry out interviews.
- This is potentially a hard to recruit population, so we suggest that you open up recruitment across the UK, not just in the north of England. This will save time with an amendment later.
- O Clarify in this section your rational for only carrying out interviews on University premises. We suggest that you make this a phone interview study, and offer face to face home visits to participants in a limited radius of the University, amending your application to take this approach into account, including the incorporation of the exact details of the lone worker process you would follow and approach. The committee is concerned that you acknowledge these participants are likely to find the campus intimidating, difficult to access, hard to find their way around. Not only could this be a source of discomfort for the participants but this could impact on your recruitment.
- Describe exactly the process you will put in place should a participant disclose some harm to them or others. i.e. you will first talk with your supervisors and then with their support with an appropriate agency.
- Clarify here that you will be carrying out the transcription.

#### Application section 21

- It is not usual to expect participants to maintain anonymity in an interview. This is at odds with providing a safe, relaxed space for the interview. Data should be managed and anonymised post-interview. Please amend this accordingly
- Clarify where re the participant personal details will be kept, in what manner and for how long. Note that they should be kept separately from data, in a secure locked cabinet in locked office or in a separate file on the password, encrypted server. They should be deleted once the thesis has been assessed.
- Audio files can also be deleted once the thesis is assessed; you will only need to store text data for 10 years.
- Please note that the Faculty does not have a research co-ordinator. You are responsible for ensuring the data is stored securely on the server. DClinPsy will support you to have access to a folder on the R drive for storage of anonymised data.

## Application section 22

- Move all comments relating to audio files from section 21 to this section. Audio files are included as a separate item on the application form since they contain more easily identifiable, and therefore sensitive data
- State that data on portable devices will be encrypted; if it cannot be encrypted
  can you confirm that any identifiable data (including recordings of participants'
  voices) will be deleted from the recorder as quickly as possible (eg when it has
  been transferred to a secure medium, such as a password protected PC) and in
  the meantime the recorder will be stored securely.

#### Application section 23

o Please note here if you intend to present your findings at any conferences.

## • Appendix A – interview schedule

Add a note to clarify if these are going to be indicative prompts or that you
intend to ask these in sequence, such that the session is more like a structured
qualitative interview.

### • Participant Information Sheet

- Please amend Susan Cartwright's details to those of Prof Bruce Hollingsworth, who is now Head of Division.
- Complaints section: Please add Prof Roger Pickup, Associate Dean for Research, Faculty of Health and Medicine (Division of Biomedical and Life Sciences), Lancaster University, Lancaster LA1 4YD (email r.pickup@lancaster.ac.uk, Tel: (01524) 593746) as an additional contact for complaints

#### Consent form

 Item 10 – we recommend that you delete audio files once your thesis has been assessed. Amend this item accordingly.

In addition to the above a number of minor changes and typos are noted on your application form, attached with this letter. Please address these, as well as the matters above.

Ensure consistency between the application form, the Research Protocol and the supporting materials in line with the changes requested above.

Please use Lancaster University letter-headed paper for all participant materials We ask that you attend to these in writing by (re)submitting to the FHMREC via Diane Hopkins (d.hopkins@lancaster.ac.uk) the application document and materials with any changes highlighted. If your responses to the above are satisfactory then approval will be recommended on Chair's action. If you have questions, please feel free to contact me.

Yours sincerely,

Prof Roger Pickup

R. W. Pakup

Chair of the Faculty of Health and Medicine Research Ethics Committee

Lancaster University

# FHMREC Application Form (Requested Amendments Highlighted)



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

# Application for Ethical Approval for Research involving direct contact with human participants

Instructions[guidance 1] [for additional advice on completing this form, hover PC mouse over 'guidance']

- 1. Apply to the committee by submitting:
  - a. The University's Stage 1 Self Assessment (part A only) and the Project Questionnaire. These are available on the Research Support Office website: <u>U Ethics[guidance 2]</u>
  - b. The completed application FHMREC guidance 3] form
  - Your full research proposal (background, literature review, methodology/methods, ethical considerations)
  - d. All accompanying research materials such as, but not limited to,
    - 1) Advertising materials (posters, e-mails)
    - 2) Letters/emails of invitation to participate
    - 3) Participant information sheets[guidance 4]
    - 4) Consent forms[guidance 5]
    - 5) Questionnaires, surveys, demographic sheets
    - 6) Interview schedules, interview question guides, focus group scripts
    - 7) Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing handbooks or measures, which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

- Submit all the materials electronically as a SINGLE guidance 6] email attachment in PDF format by the
  deadline date.
- Submit one <u>collated</u> and <u>signed</u> paper copy of the full application materials in time for the FHMREC meeting. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
- Committee meeting dates and application submission dates are listed on the <u>FHMREC website</u>.
   Applications must be submitted by the deadline date, to:

Dr Diane Hopkins

B14, Furness College

Lancaster University,

LA1 4YG

d.hopkins@lancaster.ac.uk

- 5. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application
- 6. Attend the committee meeting on the day that the application is considered, if required to do so.
- 1. Title of Project [guidance 7]: The experiences of clients who drop out of Cognitive Behavioural Therapy (CBT): A qualitative exploration
- 2. Name of applicant/researcher: Kay Brewster
- 3. Type of study
- Includes direct involvement by human subjects.

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: <u>LU Ethics</u> . Submit this, along with all project documentation, to Diane Hopkins.				
4. If this is a student project, please indicate what type of project by marking the relevant box: (please note that UG and taught PG projects should complete <b>FHMREC form UG-tPG</b> , following the procedures set out on the <a href="FHMREC website">FHMREC website</a>				
PG Diploma Masters dissertation DClinPsy SRP PhD Thesis PhD Pall. Care				
PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health MD				
DClinPsy Thesis 🖂				
Applicant Information				
5. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist				
6. Contact information for applicant:  E-mail: k.brewster@lancaster.ac.uk  Telephone: 07824110769 (personal mobile) (please give a number on which you can be contacted at short notice)  Address: Clinical Psychology, Division of Health Research, Furness College, Lancaster University, Lancaster. LA1  4YG				
7. Project supervisor(s), if different from applicant: 1) Pete Greasley & 2) Martin Tighe				
8. Appointment held by supervisor(s) and institution(s) where based (if applicable): 1) Research Tutor, Lancaster University & 2) Consultant Clinical Psychologist, LCFT				
9. Names and appointments of all members of the research team (including degree where applicable)				
Kay Brewster, BSc Psychology, MSc Health Psychology Pete Greasley, PhD Dr Martin Tighe, DClinPsy				
The Project  NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.				
10. Summary of research protocol in lay terms (indicative maximum length 150 words guidance 8):				
Cognitive Behavioural Therapy (CBT) is the dominant therapeutic approach for mental health across a range of contexts. However, each year many clients decide to 'drop-out' of CBT before the end of the agreed timescale. Quantitative studies have identified numbers of clients who drop-out but there has been little qualitative insight into the reasons why clients may decide to disengage. The current study aims to address this gap by exploring the individual experiences of adults who have chosen to drop out of individual CBT in the community. Eight to twelve participants will be recruited via social media and online support organisations across the UK. Semi-structured interviews will be conducted either face-to-face or via telephone and then analysed using a phenomenologically informed thematic analysis. For the current study, only the experiences of individuals who have attended face-to-face CBT in the community will be included i.e. not those who have accessed CBT via telephone or internet or in a self-directed format.				

#### 11. Anticipated project dates (month and year only [guidance 9])

Start date: January 2015 End date: June 2015

12. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender guidance 10]):

Eight to twelve participants will be interviewed, based on the following:

#### Inclusion Criteria:

• Male and female adults who have accessed individual CBT for any mental health need, in a community-based setting within the last 12 months with any qualified therapist, and who have independently chosen to disengage from the therapy prematurely (i.e. before the end of the predetermined timescale).

#### Exclusion criteria:

- Individuals for whom English is not their first language, and who would thus require access to translation services. Although acknowledged as a limitation of the study, the use of translators may significantly influence the accuracy, richness and content of the data obtained and would also influence the homogeneity of the sample.
- Individuals who have accessed self-directed CBT or CBT via telephone appointments.
- Individuals who have accessed CBT in non-community settings e.g. inpatient or forensic.
- Individuals who are unable to participate in the interview process (either via telephone or in person).
- Individuals who have engaged in therapy other than CBT, CBT with a group-based component or a mixed-model approach.
- Individuals who are actively distressed at the time of the interview. As participants may have ongoing mental health difficulties, prior to the interview commencing the main researcher will ensure that each participant is aware of the research topic and nature of interview questions and that participants are able to access some form of support network should the interview cause them distress. The remit of the researcher as unable to offer direct therapeutic support will be clarified; however the researcher will ensure that each participant is made aware of the support resources detailed on the information sheet.

## 13. How will participants be recruited and from where? Be as specific as possible guidance 11].

Participants will be recruited via a combination of online advertising via a professional account on 'Twitter' and adverts (see appendix B in attached protocol) placed in local service user support organisations across the UK. As a scoping exercise, an internet search was conducted using the terms 'mental health support group North England' which revealed thirteen organisations (see appendix C in attached protocol) that support service users with mental health needs. These organisations were contacted via e-mail to ascertain whether they would potentially be able to support recruitment. The following organisations have provisionally agreed to support recruitment in the form of either a written advert placed on their online forum/webpage or in their support centre, or a face-to-face presentation of the project at their routine support meeting:

- Rochdale Boroughwide User Forum (www.rbuf.org.uk). This is an online and face-to-face service that aims to bring communities together from across the borough in a cooperative effort to ensure that, in every aspect of mental health and social care, the needs and views of people with mental health issues and their carers are taken into account by those who purchase or provide services.
- Turn2Me (www.turn2me.org) online mental health community providing peer and professional support to those in need.
- Self Help Services (www.selfhelpservices.org.uk) online and face-to-face user-led mental health charity, providing services across the North West.
- Mental Health Forum (www.mentalhealthforum.net) Cumbria based online forum for discussion of anything relating to mental health.
- Launchpad (www.launchpadncl.org.uk) Newcastle based organisation run by and for users of mental health services.
- Sirius Project NorthWest England (http://sirius-project.org/help-in-the-uk/help-by-region/north-west-england/) A collaborative, recovery-focused website for people with past or present experience of mental health problems and their carers.

The above list is not exhaustive; the main researcher will also seek to recruit via relevant mental health chat forums and other support organisations.

A written advert (see appendix B in attached protocol) will be placed either on the webpage, online forum or at a local support centre for each participating organisation. The advert will contain contact details for the main researcher (course-issued research mobile telephone number and the researcher's student e-mail address). This advert will also be posted on the researcher's professional Twitter account (publicly available), with an accompanying message encouraging contacts to share the advert with anybody that they think may be interested in taking part. Where appropriate/invited, the researcher will also attend a support meeting to provide further details of the project in person. When contacted, the main researcher will discuss the project further with individual participants to determine whether the inclusion/exclusion criteria apply. Any eligible participant who is willing to proceed to interview will then be sent an information sheet (see appendix D in attached protocol), either to a postal address or via e-mail. Following this, a date and time for interview will be arranged; either via telephone or face-to-face at their home address, if within a 100 mile radius of Lancaster University. Recruitment will continue until sufficient participant numbers have been interviewed.

#### 14. What procedure is proposed for obtaining consent [guidance 12]?

All participants (who demonstrate an interest in the project) will be asked to sign a consent form prior to being interviewed (see appendix E in attached protocol). For telephone interviews, the form will be sent to a postal address and the participant will be asked to complete and return it in advance of the interview (A SAE will be provided for this purpose). The form covers all aspects of data collection, handling and storage; proposed dissemination strategy including potential publication; and confidentiality, anonymity and withdrawal policies and procedures.

15. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks guidance 13.

#### Potential distress

Although it is not anticipated that the nature of the research and interview content will provoke a distress response, there is a possibility that participants may become distressed during or following the interview. All participants will have experienced CBT for a mental health need and may have on-going mental health difficulties which may be exacerbated by discussing their experience of therapy. At the start of each interview, the main researcher will ensure that each participant is aware of their right to take a break or stop the interview and will also discuss existing or recommended support networks available, as detailed on the participant information sheet.

Should distress occur during the interview, the chief investigator will explore the nature of the distress with the participant and ascertain whether they would like to continue with the interview. Participants will also be given contact numbers for confidential support organisations, should they wish to speak to someone unconnected to either the research process, or their care. If the chief investigator deems the participant to be at immediate risk of harm, this will be discussed and the relevant authority contacted i.e. mental health crisis service. This may potentially be more difficult for telephone interviews, in which the participant may not have provided any contact information. These limitations will be discussed with the participant prior to the interview commencing and the researcher will draw on their own clinical skills in managing any distress that arises. Further, as participants will largely be recruited from within mental health support organisations, it is anticipated that they will have an existing source of support that they can access in the event of distress.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take guidance 14).

## Lone working

Interviews conducted face-to-face in participants' homes will involve lone working. Any incident of lone working will be risk assessed by the chief investigator, in consultation with both supervisors, and the Lancashire Care Foundation Trust Lone Working Policy (2013 version) will be adhered to at all times.

Interviews will be held within office hours, and, for home visits, a peer 'buddy' system will be used, as follows: The 'buddy' (another DClinPsy trainee) will be informed of the date and time for each home interview and will ensure that they are available to receive a telephone call from the researcher at a pre-designated time, following each interview. The researcher will also provide the buddy with an email with a password-protected document containing details of the participant address, which they will only open if they deem the researcher to be in danger. Once the researcher has made contact with the buddy following each interview, the buddy will delete the password-protected document. A safety plan will be agreed whereby if the buddy has not heard from the chief investigator at the agreed time, they will attempt to make contact, then open the document to retrieve the address details and contact the Police if unable to confirm the safety of the chief investigator. A safety phrase e.g. "I've left a file on my desk, could you please put it away" will also be agreed between the researcher and buddy, whereby if the researcher feels at risk they can call the buddy and state the phrase which will alert the buddy to their need for assistance. The buddy will then contact the Police.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study[guidance 15].

There may be no direct benefit to participation in this study; however participants may derive some positive benefit from being provided with the opportunity to share and reflect on their experiences. More broadly, findings from the project will further our knowledge of the reasons that clients drop out of therapy, with specific reference to CBT.

- 18. Details of any incentives/payments (including out-of-pocket expenses) made to participants [guidance 16]: No incentives will be provided and no travel costs will be incurred by participants as the interviews will be conducted at participant home addresses or via telephone.
- 19. Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality[guidance 17].

Since the aim of this research is to better understand the direct and detailed experiences of individual clients, an inductive phenomenological qualitative approach using semi-structured interviews will be used. An interview schedule will be used (see appendix A in attached protocol), in order to "facilitate an interaction which permits participants to tell their own stories, in their own words" (Smith, Flowers & Larkin, 2009, p. 57). The schedule contains the following general areas for discussion in order to guide the interviews based on the research topic; however as far as possible the participants will be supported to share their experiences in an individualised way:

- Why the client accessed therapy and whether they chose CBT
- ii. Experience of therapy content and process
- iii. Circumstances leading to drop out and process by which this was done

Participants will be invited to attend a one-off interview, either at their home address (if within a 100 mile radius of Lancaster University) or via telephone, in order to facilitate inclusion of those participants who would be unable to travel to interview or who prefer to remain visually anonymous. Interviews will be conducted by the chief investigator and will last between 30 minutes and one hour. Following completion of the consent form, participants will be invited to choose a pseudonym for the purposes of the interview and report and will also be asked a series of descriptive questions (see appendix A in attached protocol), in order to collect basic demographic information about the sample. Participants will be advised that they can stop or take a break during the interview at any point, and an agreement will be made prior to the interview commencing as to how best this can be communicated.

Confidentiality between chief investigator and participant will be maintained other than in the event of a disclosure that indicates that "the health, safety or welfare of the client or someone else would otherwise be put at serious risk" (British Psychological Society, 2008, p.9). Participants will be informed of the limits to confidentiality at first contact (on the initial information sheet, then also verbally prior to the start of the interview). If a participant who is interviewed by telephone (and therefore anonymous) discloses anything that falls under the above definition, the researcher will encourage them to share this disclosure with the appropriate

service, or to provide the researcher with additional contact information to share the disclosure on their behalf. If the risk to self or others is deemed severe and the participant does not consent to share the disclosure the researcher will consult their research supervisors and agree on an appropriate action, which may include involvement of emergency services.

The main researcher will be responsible for transcribing the interview audio files. An inductive, contextualist thematic analysis will be used to analyse the interview transcripts, based on suggested guidance by Braun and Clarke (2006). A contextualist approach "acknowledge(s) the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of reality" (p.81).

By this method, data will be coded without trying to fit it into a pre-conceived theoretical framework based on existing research. Data will be analysed at the latent level, which "goes beyond the semantic content of the data, and starts to identify or examine the underlying ideas, assumptions, and conceptualisations – and ideologies - that are theorised as shaping or informing the semantic content of the data" (p. 84).

A clear audit trail will be presented within the final report, in order to evidence how findings have emerged. The academic supervisor will have access to the transcripts, and will assist the chief investigator in the coding and development of themes. The field supervisor will also assist with the development of themes once the data has been coded and is thus less potentially identifiable. In the unlikely event that either supervisor is incapacitated at this stage of the research process, an alternative member of the DClinPsy teaching or research team, with equivalent qualification, will be approached to assist.

20. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research guidance 18].

As the interviews are only semi-structured, the researcher will be guided by each participant in the course of data collection as to specific details of experiences covered.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998 [guidance 19].

Participant identifying information such as name/address/demographic information will be stored as a password-protected document on the password protected University server. Only the main researcher will have access to this password (where individual addresses are shared with the buddy as part of the lone worker safety plan, a different password will be used and the main researcher will take responsibility to ensure that this information is deleted following each home interview). On completion and assessment of the project, this information will be deleted.

Hard copies of the consent forms will be scanned electronically and saved onto the password encrypted University server. The hard copies will be stored securely in a locked filing cabinet until the thesis is submitted and assessed and the hard copies will be destroyed (shredded via the confidential waste system). Following completion of the project the electronic scanned copies of the consent forms, along with files containing the study data (anonymised transcripts, theme development and the final study report) will be stored within a folder on the password encrypted University R Drive for a period of 10 years as per University policy. Participants will be informed of this and appropriate consent obtained.

22. Will audio or video recording take place?	no	$oxed{\boxtimes}$ audio	video	
If yes, what arrangements have been made for	or audio/vide	o data storage? A	t what point in t	he research wil
tapes/digital recordings/files be destroyed gui	idance 20]?			

Interviews will be recorded on a portable audio recorder. It is not possible to encrypt the data at this stage; however each audio recording will be transferred to the password encrypted University server as quickly as possible following each interview, using an additional software encryption program that can only be accessed by the main researcher. The recording device will be stored securely (in a locked compartment of the main researcher's car whilst travelling from each interview to the University. For telephone interviews, a microphone 'pick-up' device will be used, to facilitate the capturing of the interview data by the audio recorder. Once saved onto the university server, the audio recordings will be deleted from the audio recorder. The University server is encrypted and password-protected and is also backed up regularly, thus minimising the chances of the audio files being lost or accessed inappropriately. Participants will be asked to choose a pseudonym, which will be used

post-interview in order to ensure anonymity in the transcripts and final report. Following assessment of the project, the audio files will be deleted from the University server.

23. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis guidance 21].

A brief report containing a written summary of the themes will be shared with participants (if they choose). The main researcher will present an overview of the project to peers as part of the DClinPsy teaching programme. Following attendance at thesis viva meeting, and completion of any amendments, the thesis will be published and made publicly available. At this stage, components of the thesis may also be submitted for publication in appropriate journals and/or presented at appropriate conferences.

24. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study[guidance 22]? Are there any matters about which you wish to seek guidance from the FHMREC?

As recruitment will largely be through online support organisations, it will be essential to ensure that the confidentiality and anonymity already conferred by these organisations is maintained with individual participants i.e. although the identity of participants may be revealed to the researcher, this information will not be shared with other members or leaders of the organisations involved.

Signatures:	Applicant guidance 23]:				
	Date:				
	*Project Supervisor (if applicable):				
	Date:				

<sup>\*</sup>I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

## Appendix 4-1

# Research Protocol V2 with Amendments Highlighted



## Lancaster DClinPsy Thesis - Research Protocol (Version 2)

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#### Title

The experiences of clients who drop-out of Cognitive Behavioural Therapy (CBT): A qualitative exploration

#### Introduction

Cognitive Behavioural Therapy (CBT) currently occupies a dominant position in comparison to other therapeutic models within best practice clinical guidelines.

CBT is recommended as a key intervention for individuals that meet the diagnostic criteria for Depression, Anxiety Disorders, Schizophrenia and Bipolar Disorder, in addition to several other physical and emotional difficulties.

CBT can be delivered by a range of qualified practitioners, including Psychologists, Nurses and Psychotherapists. There are different formats, depending on individual need, which include individual therapy, group therapy and guided self-help. CBT is based on the notion that "...dysfunctional thinking is common to all



psychological disturbances. When people learn to evaluate their thinking in a more realistic and adaptive way, they experience improvement in their emotional state and in their behaviour" (Beck, 2011, p.3). Therapy involves various tasks aimed at changing an individual's thoughts and behaviour, so as to reduce emotional distress.

Extensive research has highlighted the effectiveness of CBT in supporting positive change, generally measured by symptom reduction on objective outcome measures, as defined by diagnostic criteria. A recent review of 106 existing meta-analyses by Hofmann, Asnaani, Vonk, Sawyer and Fang (2012) found that the use of CBT was most strongly supported for anxiety disorders, somatoform disorders, bulimia, anger control problems, and general stress.

Previous research into therapy effectiveness within and between different therapeutic models has resulted in a 'common factors model' by which it is believed that there exist "a set of factors that are common to all (or most) therapies ... and that these common factors are responsible for psychotherapeutic benefits rather than the ingredients specific to the particular theories" (Wampold, 2001, p.23). These common factors have been described as falling under three categories (Lambert & Ogles, 2004):

- Support factors, such as the therapeutic alliance, trust and therapist expertise
- ii. Learning factors, such as feedback and insight
- iii. Action factors, such as modelling, practise and success experience

Extensive research has been conducted which supports the common factors model, particularly highlighting importance of therapeutic alliance in predicting outcome (e.g. Martin, Garske & Davis, 2000).



Despite clear indication for the presence and central influence of common factors in predicting therapy effectiveness, the majority of research in the context of evidence-based practice has continued to focus on exploring the evidence for the effectiveness of distinct therapeutic models. This research has largely taken the form of quantitative, experimental investigations, based on a medical model of symptom reduction as an indicator of successful outcome. This in turn has led to a bias towards the use of quantitative, objective outcome measures across therapeutic services based primarily on symptom reduction in accordance with a diagnostic framework.

In addition to studies exploring therapy effectiveness, some researchers have sought to explore the phenomenon of therapy 'drop out' - a concept that has been conceptualised in several different ways within existing research. Based on their literature review exploring drop out from family and marriage therapy, Werner-Wilson and Winter (2010) identify three definitions of therapy dropout:

- The client fails to attend a specified number of sessions, regardless of outcome at that point
- The client chooses not to continue after a certain point in a prescheduled timeframe for the therapy, as they believe their goals to have been met
- iii. The client terminates therapy without having fulfilled their therapeutic goals, regardless of how many sessions or length of time they have already spent in therapy

There is overlap between these definitions; however the main distinction is the relative responsibility or power attributed to the therapist and client in each. The three types of drop out could potentially result from very different experiences, as reflected in several existing studies.



Recent research findings have indicated that, in general, approximately twenty per cent of individuals drop out of therapy before the predetermined timeframe has elapsed (Swift & Greenberg, 2012). Several reasons for this have been suggested, such as the way the therapy is delivered and systemic context i.e. inherent pressure associated with inpatient environment (Chiesa, Drahorad & Longo, 2000); financial constraints and other life demands (Swift & Greenberg, 2012) or a therapeutic rupture, whereby conflict arises between client and therapist (Knox et al., 2011). In a quantitative study exploring the views of both clients and therapists, Westmacott, Best, Rumstein-McKean and Schindler (2010) found that contextual factors (such as those described above) affecting premature therapy termination can have differing levels of influence, depending on whether the decision to terminate is made independently by the client, or as a result of a mutual agreement between client and therapist.

Two recent studies have directly explored clients' views on individual therapy drop out from within a qualitative design. In Knox et al's study (2011), twelve clients were interviewed about their experiences of premature termination from individual therapy (including, but not limited to, CBT). As recruitment was largely via the researchers' professional networks and academic contacts, eleven of the participants had training at Masters or Doctorate level in a mental health profession. Five of the participants described their termination from therapy in 'positive terms', based on logistic or financial constraints rather than a negative experience of therapy. The other seven participants described a generally positive experience of the therapy, but detailed negative experiences of the therapist or therapeutic relationship that ultimately had led them to terminate therapy abruptly and without discussion with their therapist. There were limitations to the study in that the majority of participants



were trained mental health professionals, and thus may have had different expectations or prior knowledge of therapy. All but one of the participants were female and the inclusion of a range of therapy approaches may also have influenced findings, as it is difficult to establish whether individual experiences were due to the model of therapy experienced or other factors.

Piselli, Halgin and MacEwan (2011) conducted a qualitative exploration of the experiences of therapists when clients terminate therapy prematurely. Eleven practising clinical psychotherapists were interviewed, who identified themselves as using an eclectic or integrative approach (the authors chose to dissociate the research from any particular theoretical orientation or therapy model). Participants were asked to describe an experience of premature therapy termination based on a client "whose primary diagnosis was not an Axis I psychotic or substance abuse disorder or an Axis II personality disorder" (p. 403). Findings indicated a range of explanations for premature termination which were classified as factors relating to the client, the therapist or the therapeutic relationship. Client factors included interfering life circumstances, avoidance or dissatisfaction with treatment progress, which could be negatively influenced by a poor therapeutic alliance or disagreement over treatment goals. These issues could be further exacerbated by therapist factors, such as hurrying interventions, failing to recognise or address problems or making errors. Again, the study had limitations associated with the inclusion of a range of therapy approaches and the exclusion of experiences of clients with particular diagnoses.

These studies explored therapy drop out across client populations and therapeutic models. There exists only limited research into client drop out from CBT specifically and of that research, the majority of published studies have focused on quantitative outcomes rather than on gaining detailed qualitative insight into the



reasons why clients drop out. There have been two exceptions, which have explored this phenomenon from a qualitative design. In an Australian study, Dunn, Delfabbro and Harvey (2012), interviewed five clients via telephone to explore their experiences of premature drop out from CBT for problem gambling. The authors found that factors such as unexpected lifestyle changes and (lack of) readiness to engage and change were a key aspect of participants' experiences, but that some clients had also terminated therapy prematurely as they felt that they had learned sufficient skills to continue independently (i.e. would not consider themselves as having 'dropped out' despite their therapist feeling that they should have continued to the end of the predetermined timescale). The findings were conceptualised within the theoretical framework of problem gambling and as such, cannot be generalised. However, the experiences shared by participants when interviewed directly offered new insights into factors influencing therapy drop out and as such, further qualitative research in this area is indicated. Barnes et al. (2013) utilised a mixed-method approach by which, as part of a broader randomised controlled trial investigating depressed clients' experiences of individual CBT, they included an enmeshed qualitative follow-up exploration, via in-depth interview, of 26 clients who had dropped out of therapy. Findings indicated that factors such as the difficulty in discussing painful experiences, the homework component of CBT and issues within the therapeutic relationship contributed to therapy drop out. The study was limited in exploring the views of individuals with a diagnosis of Depression and in the context of a research trial into CBT.

The current study therefore aims to address the gap in existing qualitative research by exploring the direct experiences of clients who have prematurely dropped out of community-based, face-to-face CBT, outside of a research trial context and not limited to users of NHS services.



Results of the study will further our existing knowledge of factors influencing therapy effectiveness and offer a specific insight into how CBT is experienced by those who choose to disengage within the predetermined timescale.

#### **Research Questions**

The aim of this study is to explore the experiences of clients' who drop-out of Cognitive Behaviour Therapy (CBT). Specifically, to explore factors influencing CBT drop-out in adults in a community, face-to-face context and to consider these factors in relation to the specific theoretical orientation and approach of CBT.

#### Method

### Design

Since the aim of this research is to better understand the direct and detailed experiences of individual clients, an inductive phenomenological qualitative approach using semi-structured interviews will be used.

#### Materials

An interview schedule will be used (see appendix A), in order to "facilitate an interaction which permits participants to tell their own stories, in their own words" (Smith, Flowers & Larkin, 2009, p. 57). The schedule contains the following general areas for discussion in order to guide the interviews based on the research topic; however as far as possible the participants will be supported to share their experiences in an individualised way:

- i. Why the client accessed therapy and whether they chose CBT
- ii. Experience of therapy content and process
- iii. Circumstances leading to drop out and process by which this was done



#### **Participants**

Adults who have chosen to disengage prematurely from CBT will be recruited from across the UK, via social media and various support organisations (see 'recruitment' section below for full details) and invited to be interviewed either face-to-face or via telephone. The following inclusion/exclusion criteria will be used:

#### Inclusion Criteria:

Male and female adults who have accessed individual CBT for any mental
health need, in a community-based setting within the last 12 months with
any qualified therapist, and who have independently chosen to disengage
from the therapy prematurely (i.e. before the end of the predetermined
timescale).

#### Exclusion criteria:

- Individuals for whom English is not their first language, and who would
  thus require access to translation services. Although acknowledged as a
  limitation of the study, the use of translators may significantly influence
  the accuracy, richness and content of the data obtained and would also
  influence the homogeneity of the sample.
- Individuals who have accessed self-directed CBT or CBT via telephone appointments.
- Individuals who have accessed CBT in non-community settings e.g. inpatient or forensic.
- Individuals who are unable to participate in the interview process (either via telephone or in person).
- Individuals who have engaged in therapy other than CBT, CBT with a group-based component or a mixed-model approach.



• Individuals who are actively distressed at the time of the interview. As participants may have ongoing mental health difficulties, prior to the interview commencing the main researcher will ensure that each participant is aware of the research topic and nature of interview questions and that participants are able to access some form of support network should the interview cause them distress. The remit of the researcher as unable to offer direct therapeutic support will be clarified; however the researcher will ensure that each participant is made aware of the support resources detailed on the information sheet.

Since I am aiming for rich detailed accounts of client experiences, the number of interviews will be limited to between eight and twelve. This figure accords with current guidelines for inductive phenomenological qualitative research of this nature, where a homogenous sample is involved (Guest, Bunce & Johnson, 2006).

#### Procedure

#### Recruitment

The sampling method will be purposive and participants will be recruited via a combination of online advertising via a professional account on 'Twitter' and adverts (see appendix B) placed in local service user support organisations across the UK, in addition to the DClinPsy newsletter.

As a scoping exercise, an internet search was conducted using the terms 'mental health support group North England' which revealed thirteen organisations (see appendix C) that support service users with mental health needs. These organisations were contacted via e-mail to ascertain whether they would potentially be able to support recruitment. The following organisations have provisionally agreed to support recruitment in the form of either a written advert placed on their online



forum/webpage or in their support centre, or a face-to-face presentation of the project at their routine support meeting. The other organisations will also be approached, following ethical approval:

- Rochdale Boroughwide User Forum (www.rbuf.org.uk). This is an
  online and face-to-face service that aims to bring communities together
  from across the borough in a cooperative effort to ensure that, in every
  aspect of mental health and social care, the needs and views of people
  with mental health issues and their carers are taken into account by
  those who purchase or provide services.
- Turn2Me (<u>www.turn2me.org</u>) online mental health community providing peer and professional support to those in need.
- Self Help Services (<u>www.selfhelpservices.org.uk</u>) online and face-toface user-led mental health charity, providing services across the North West.
- Mental Health Forum (<u>www.mentalhealthforum.net</u>) Cumbria based online forum for discussion of anything relating to mental health.
- Launchpad (<u>www.launchpadncl.org.uk</u>) Newcastle based organisation run by and for users of mental health services.
- Sirius Project NorthWest England (<a href="http://sirius-project.org/help-in-the-uk/help-by-region/north-west-england/">http://sirius-project.org/help-in-the-uk/help-by-region/north-west-england/</a>) A collaborative, recovery-focused website for people with past or present experience of mental health problems and their carers.



The above list is not exhaustive; the main researcher will also seek to recruit via relevant mental health chat forums and other support organisations. A written advert (see appendix B) will be placed either on the webpage, online forum or at a local support centre for each participating organisation, and in the DClinPsy course newsletter (pending permission). The advert will contain contact details for the main researcher (course-issued research mobile telephone number and the researcher's student e-mail address). This advert will also be posted on the researcher's professional Twitter account (publicly available), with an accompanying message encouraging contacts to share the advert with anybody that they think may be interested in taking part. Where appropriate/invited, the researcher will also attend a support meeting to provide further details of the project in person. When contacted, the main researcher will discuss the project further with individual participants to determine whether the inclusion/exclusion criteria apply. Any eligible participant who is willing to proceed to interview will then be sent an information sheet (see appendix D), with SAE included, to a postal address. Following this, a date and time for interview will be arranged; either via telephone or face-to-face at their home address, if within a 100 mile radius of Lancaster University. Recruitment will continue until sufficient participant numbers have been interviewed.

#### Consent

All participants (who demonstrate an interest in the project) will be asked to sign a consent form prior to being interviewed (see appendix E). For telephone interviews, the form will be sent to a postal address and the participant will be asked to complete and return it in advance of the interview (A SAE will be provided for this purpose). The form covers all aspects of data collection, handling and storage;



proposed dissemination strategy including potential publication; and confidentiality, anonymity and withdrawal policies and procedures.

### **Interview process**

Participants will be invited to attend a one-off interview, either at their home address (if within a 100 mile radius of Lancaster University, for practicality) or via telephone, in order to facilitate inclusion of those participants who would be unable to travel to interview or who prefer to remain visually anonymous. Interviews will be conducted by the chief investigator and will last between up to one hour. Following completion of the consent form, participants will be invited to choose a pseudonym for the purposes of the interview and report and will also be asked a series of descriptive questions (see appendix A), in order to collect basic demographic information about the sample. Participants will be advised that they can stop or take a break during the interview at any point, and an agreement will be made prior to the interview commencing as to how best this can be communicated.

#### **Ethical Considerations**

## Potential disclosure or complaint

Confidentiality between chief investigator and participant will be maintained other than in the event of a disclosure that indicates that "the health, safety or welfare of the client or someone else would otherwise be put at serious risk" (British Psychological Society, 2008, p.9). Participants will be informed of the limits to confidentiality at first contact (on the initial information sheet, then also verbally prior to the start of the interview). If a participant who is interviewed by telephone (and therefore anonymous) discloses anything that falls under the above definition, the



researcher will encourage them to share this disclosure with the appropriate service, or to provide the researcher with additional contact information to share the disclosure on their behalf. If the risk to self or others is deemed severe and the participant does not consent to share the disclosure the researcher will consult their research supervisors and agree on an appropriate action, which may include involvement of emergency services.

#### Potential distress

Although it is not anticipated that the nature of the research and interview content will provoke a distress response, there is a possibility that participants may become distressed during or following the interview. All participants will have experienced CBT for a mental health need and may have on-going mental health difficulties which may be exacerbated by discussing their experience of therapy. At the start of each interview, the main researcher will ensure that each participant is aware of their right to take a break or stop the interview and will also discuss existing or recommended support networks available, as detailed on the participant information sheet. Should distress occur during the interview, the chief investigator will explore the nature of the distress with the participant and ascertain whether they would like to continue with the interview. Participants will also be given contact numbers for confidential support organisations, should they wish to speak to someone unconnected to either the research process, or their care. If the chief investigator deems the participant to be at immediate risk of harm, this will be discussed and the relevant authority contacted i.e. mental health crisis service. This may potentially be more difficult for telephone interviews, in which the participant may not have provided any contact information. These limitations will be discussed with the participant prior to the interview commencing and the researcher will draw on their



own clinical skills in managing any distress that arises. Further, as participants will largely be recruited from within mental health support organisations, it is anticipated that they will have an existing source of support that they can access in the event of distress.

## Requests for additional attendees at interview

If a participant requests to have an additional person present at interview e.g. for physical or emotional support, this will be permitted on the premise that the additional attendee will be asked to maintain silence during the interview and also to maintain confidentiality following the interview. They will also be informed that any contribution they do make will not be used or included in the analysis.

### **Practical Issues**

### Lone working

Lone working

Interviews conducted face-to-face in participants' homes will involve lone working. Any incident of lone working will be risk assessed by the chief investigator, in consultation with both supervisors, and the Lancashire Care Foundation Trust Lone Working Policy (2013 version) will be adhered to at all times.

Interviews will be held within office hours, and, for home visits, a peer 'buddy' system will be used, as follows:

The 'buddy' (another DClinPsy trainee) will be informed of the date and time for each home interview and will ensure that they are available to receive a telephone call from the researcher at a pre-designated time, following each interview. The researcher will



also provide the buddy with an email with a password-protected document containing details of the participant address, which they will only open if they deem the researcher to be in danger. Once the researcher has made contact with the buddy following each interview, the buddy will delete the password-protected document. A safety plan will be agreed whereby if the buddy has not heard from the chief investigator at the agreed time, they will attempt to make contact, then open the document to retrieve the address details and contact the Police if unable to confirm the safety of the chief investigator. A safety phrase e.g. "I've left a file on my desk, could you please put it away" will also be agreed between the researcher and buddy, whereby if the researcher feels at risk they can call the buddy and state the phrase which will alert the buddy to their need for assistance. The buddy will then contact the Police.

#### **Data handling**

Participant identifying information such as name/address/demographic information will be stored as a password-protected document on the password protected University server. Only the main researcher will have access to this password (where individual addresses are shared with the buddy as part of the lone worker safety plan, a different password will be used and the main researcher will take responsibility to ensure that this information is deleted following each home interview). On completion and assessment of the project, this information will be deleted.

Interviews will be recorded on a portable audio recorder. It is not possible to encrypt the data at this stage; however each audio recording will be transferred to the password encrypted University server as quickly as possible following each interview,



using an additional software encryption program that can only be accessed by the main researcher. The recording device will be stored securely (in a locked compartment of the main researcher's car whilst travelling from each interview to the University. For telephone interviews, a microphone 'pick-up' device will be used, to facilitate the capturing of the interview data by the audio recorder. Once saved onto the university server, the audio recordings will be deleted from the audio recorder. The University server is encrypted and password-protected and is also backed up regularly, thus minimising the chances of the audio files being lost or accessed inappropriately. Participants will be asked to choose a pseudonym, which will be used post-interview in order to ensure anonymity in the transcripts and final report. Following assessment of the project, the audio files will be deleted from the University server.

Hard copies of the consent forms will be scanned electronically and saved onto the password encrypted University server. At this point, the hard copies will be destroyed (shredded via the confidential waste system). Following completion of the project the electronic scanned copies of the consent forms, along with files containing the study data (anonymised transcripts, theme development and the final study report) will be stored within a folder on the password encrypted University R Drive for a period of 10 years as per University policy. Participants will be informed of this and appropriate consent obtained.

#### **Proposed Analysis**

The main researcher will be responsible for transcribing the interview audio files. An inductive, contextualist thematic analysis will be used to analyse the interview transcripts, based on suggested guidance by Braun and Clarke (2006). A contextualist approach "acknowledge(s) the ways individuals make meaning of their



experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of reality" (p.81).

By this method, data will be coded without trying to fit it into a pre-conceived theoretical framework based on existing research. Data will be analysed at the latent level, which "goes beyond the semantic content of the data, and starts to identify or examine the underlying ideas, assumptions, and conceptualisations – and ideologies - that are theorised as shaping or informing the semantic content of the data" (p. 84).

A clear audit trail will be presented within the final report, in order to evidence how findings have emerged. The academic supervisor will have access to the transcripts, and will assist the chief investigator in the coding and development of themes. The field supervisor will also assist with the development of themes once the data has been coded and is thus less potentially identifiable.

#### Dissemination strategy

A brief report containing a written summary of the themes will be shared with participants (if they choose). The main researcher will present an overview of the project to peers as part of the DClinPsy teaching programme. Following attendance at thesis viva meeting, and completion of any amendments, the thesis will be published and made publicly available. At this stage, components of the thesis may also be submitted for publication in appropriate journals and/or presented at appropriate conferences.

# **Contingency Planning**

In the event that the academic supervisor is unavailable (e.g. due to sickness or long-term leave) to provide input in the form of draft reading and/or analysis of data,



an alternative member of the DClinPsy teaching team will be approached. In this instance, this staff member will have access to the interview transcripts as required.

# **Proposed Timescale**

January 2014	Initial project proposal presentation to peers and 2 members of the DClinPsy research team at University.
March 2014	Presentation of amended proposal to peers and 2 members of the DClinPsy research team at University.
April – July 2014	Identification of appropriate field supervisor
July - September 2014	Development and revision of protocol and completion of FHMREC documentation.
October - December 2014	Submission of FHMREC documentation and attendance at meeting, amendments to ethics form.
January – February 2015	Recruitment and participant interviews
January – March 2015	Data analysis and write-up
March 2015	Initial draft read and necessary amendments
April 2015	Further draft read and necessary amendments.
May – July 2015	Submission to University of final report. Attendance at Viva meeting and amendments where indicated. Dissemination of summary report to participants.



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# Appendix A: Interview Schedule

# PART A. Descriptive Information

- Age when attended CBT: 18-24, 25-34, 35-44, 45-54, 55-64, 65+
- Gender
- · Type of CBT accessed and qualification of CBT therapist
- · Approximate date CBT started and ended
- · Details of any other previous therapy experience

NB. The following questions will be used as indicative prompts with which to guide the interview structure; however participants will also be encouraged to elaborate on other issues that they raise and which are relevant to the research topic.

Can you tell me about the reasons you had for accessing CBT?

- How were you referred?
- What qualification did your therapist have?
- Did you have a choice of therapy?

# What format did the CBT take?

- How many sessions and how often?
- What did you do in the sessions?
- Was there any 'homework' outside of the sessions?

# How did you get on with the therapist?

- Were there any disagreements and how were these resolved?
- How involved did you feel in the therapy process?
- How were goals and timescales agreed?

What led you to drop out of therapy?



- When did this happen?
- How did you decide?
- How did you do this?

# What effect did dropping out have on you?

- Did you seek support from an alternative source?
- Did it change your opinion of therapy more generally?
- Would you act differently if in the same position now?



#### Appendix B - written recruitment advert

# PARTICIPANTS WANTED FOR RESEARCH STUDY

Have you had experience of cognitive behaviour therapy (CBT)? Did you choose to drop out of CBT before the agreed timescale?

I am a trainee clinical psychologist based at Lancaster University. I am conducting research into the reasons that adults drop out of CBT and would really like to hear more about your experience. Interviews will be confidential and will not affect any care you currently receive.

If you would be willing to be interviewed (either face-to-face or via telephone) or would like to find out more about the project, please contact Kay Brewster (main researcher) via telephone: (research number) or e-mail: <a href="mailto:k.brewster@lancaster.ac.uk">k.brewster@lancaster.ac.uk</a>



# Appendix C: List of organisations which support individuals with mental health difficulties in the North of England

- Cumbria mental health online forum: <a href="http://www.mentalhealthforum.net/">http://www.mentalhealthforum.net/</a>
- Cumbria Mental Health Group (service user and carer led support service)
- Contact (Morpeth Mental Health Group) Ltd:
   <a href="http://www.contactmorpeth.org.uk/contactus.html">http://www.contactmorpeth.org.uk/contactus.html</a>
- Launchpad user-led group in Newcastle aimed at informing the way mental health services are led: <a href="http://launchpadncl.org.uk/">http://launchpadncl.org.uk/</a>
- Mental Health North East (MHNE) network: <a href="http://mhne.org.uk">http://mhne.org.uk</a>
- Manchester Users Network: <a href="http://www.manchesterusersnetwork.org.uk">http://www.manchesterusersnetwork.org.uk</a>
- New Way Forward: <a href="http://www.newwayforwardtrafford.org">http://www.newwayforwardtrafford.org</a>
- Rochdale Boroughwide User Forum: <a href="http://www.rbuf.org.uk/">http://www.rbuf.org.uk/</a>
- Stockport User Friendly Forum:
   <a href="http://stockportuserfriendlyforum.wordpress.com/about/">http://stockportuserfriendlyforum.wordpress.com/about/</a>
- Self Help Services North West: <a href="https://www.selfhelpservices.org.uk/">https://www.selfhelpservices.org.uk/</a>
- Sirius Project North West England: <a href="http://sirius-project.org/help-in-the-uk/help-by-region/north-west-england/">http://sirius-project.org/help-in-the-uk/help-by-region/north-west-england/</a>
- Together UK: http://www.together-uk.org
- Turn 2 Me online forum: https://forum.turn2me.org



#### Appendix D: Participant Information Sheet

# The experiences of clients who drop-out of Cognitive Behavioural Therapy (CBT): A qualitative exploration

My name is Kay Brewster and I am conducting this research as a student in the clinical psychology doctorate programme at Lancaster University, Lancaster, United Kingdom.

#### What is the study about?

The purpose of this study is to find out more about the individual experiences of adults who choose to drop-out of CBT.

#### Why have I been approached?

You have been approached because the study requires information from people who have previously engaged in individual CBT in the community.

#### Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

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

If you decide you would like to take part, you will be asked to attend one interview over the next couple of months, which can take place either via telephone or at your home (if you live within 100 miles of Lancaster University), depending on your preference. The interview will last around 30 minutes to one hour, and will be audio recorded. The information you provide in the interview will then be put together with information gathered from other participants and written up into a report which will be submitted as part of my thesis. The thesis will be published and results may also be shared with participants.

#### Will my data be confidential?

The information you provide is confidential; your name will not be recorded at interview and any identifying information will be removed from quotes before they are included in the final report. Details of the interview will not be discussed with anyone other than my academic and field supervisors (listed below). If, however, you feel you would like to discuss your involvement in the research with someone you know, that is fine.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Hard copies of transcripts from the interviews will be kept in a locked cabinet for the duration of the study, then converted to electronic files for storage by the university research coordinator on an area of the university network only they have access to. At this point, hard copies will be destroyed confidentially by the chief investigator
- Audio files will be stored securely on the university computer system. The
  files on the computer will be encrypted (that is no-one other than the
  researcher will be able to access them) and the computer itself password
  protected. These files will not be shared with anyone and will be deleted from



- the computer system at the end of the research project; once the report has been examined by the University.
- At the end of the project, electronic copies of consent forms, transcripts and the final report will be kept securely on an area of the university network for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to an appropriate member of staff about this. If possible, I will tell you if I have to do this.

#### What if I change my mind and want to withdraw my information?

If you decide after the interview that you are no longer happy for your data to be used, just contact Kay Brewster and every effort will be made to remove your data from the final analysis.

#### What will happen to the results?

The results will be written up into a report which will be submitted to the university as part of my final year thesis. A summary of the report will be shared with you and other participants. The report will also be presented to some of my colleagues as part of my assessment and may also be submitted for publication in an academic or professional journal and be presented at conferences.

#### Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress during or after participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

#### Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Findings from the study, however, will help us to present individual client views about CBT and why some people choose to drop out.

# Will I be paid for taking part?

Unfortunately we are not able to provide payment to participants.

## Who has reviewed the project?

This study has been reviewed by the University research ethics committee.



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

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

Main researcher: Kay Brewster

Phone: (research mobile tbc)

Email: k.brewster@lancaster.ac.uk

Clinical Psychology, Division of Health Research, Lancaster University, Lancaster. LA1 4YG

Academic supervisor: Dr Pete Greasley

Phone: 01524 593535

Email: p.greasley@lancaster.ac.uk

Clinical Psychology, Division of Health Research, Furness College, Lancaster University, Lancaster. LA1 4YG

Field supervisor: Dr Martin Tighe

Phone: 07507856438

Email: Martin.Tighe@lancashirecare.nhs.uk

#### **Complaints**

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

Dr Jane Simpson Professor Roger Pickup
Research Director Associate Dean for Research

Tel: 01524 592858 Tel: 01524 593746

Email: <u>i.simpson2@lancaster.ac.uk</u>

Email: <u>r.pickup@lancaster.ac.uk</u>

Division of Clinical Psychology Furness Building,

Lancaster University,

Lancaster. LA1 4YG Faculty of Health and Medicine Div. Biomedical & Life Sciences

Lancaster University, Lancaster.

LA14YD



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

Professor Bruce Hollingsworth Head of Division of Health Research

Tel: 01524 594154

Email: b.hollingsworth@lancaster.ac.uk

Faculty of Health and Medicine Furness building Lancaster University Lancaster LA1 4YG

#### Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

# **Lancashire Care Mental Health Helpline**

Freephone: 0500 639 000

Open Monday - Friday 7pm - 11pm, Saturday and Sunday 12 midday to 12 midnight

Free information and listening service

#### **Cumbria Partnership Direct**

Telephone: 0800 171 2333

24-hour helpline for residents of Cumbria with mental health problems.

# Cumbria Health on Call (CHoC)

Telephone: 03000 247 247

Open Monday to Friday 6.30pm until 8.00am

24 hours throughout the weekend

24 hour cover on Bank Holidays including Easter, Christmas and New Year For urgent out-of-hours GP contact and referral to urgent mental health services

#### Samaritans

Phone: 08457 90 90 90 E-mail: jo@samaritans.org

24 hour confidential emotional support service via telephone, e-mail or face-to-face

contact

Thank you for taking the time to read this information sheet



# **Appendix E: Participant Consent Form**

Study Title: The experiences of clients who drop-out of Cognitive Behavioural Therapy (CBT): A qualitative exploration

We are asking if you would like to take part in a research project exploring the experiences of adults who drop out of CBT in the community.

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

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



N	lame of Participant:
S	ignature:
D	Date:
N	Jame of Researcher:
S	ignature:
D	Date: