A PORTFOLIO OF ACADEMIC, THERAPEUTIC PRACTICE AND
RESEARCH WORK

Including an investigation of:

‘Closing the gap’: Personal meanings among psychotherapists working with clients
with long-term health conditions.

By

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Throughout this portfolio, the names of all clients and research participants have been replaced with pseudonyms and any other identifying information pertaining to clients, participants and clinical placements has been altered, omitted or kept to a minimum in order to maintain confidentiality.
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Abstract

This is a portfolio of academic, therapeutic practice and research work. The portfolio consists of three dossiers that reflect my professional and personal development as a counselling psychologist across three years of training. The academic dossier is comprised of three theoretical essays. The first essay explores the concept of psychological contact with clients within the person-centred model through a review and critique of a book chapter on this subject. The second essay discusses working psychodynamically with a client experiencing grief who was diagnosed with Generalised Anxiety Disorder, drawing on Klein's theory on primitive defences and Freud's paper on Mourning and Melancholia (1917). The final essay examines the clinical implications of the differences between traditional CBT and ACT when working with clients with chronic pain. The therapeutic practice dossier presents an overview of my three clinical placements and the client populations I worked with during my training as a counselling psychologist. It also contains my final clinical paper, which is a narrative of my personal and professional development throughout this course and how it has shaped me as a person and as a practitioner. Finally, the research dossier contains a literature review and two empirical research studies. The review explores and critiques the available literature on the different conceptualisations and uses of hope in counselling and psychotherapeutic practice. The first empirical piece is a Grounded Theory (GT) exploration of the experiences of people who were diagnosed with a chronic illness when they were young. The second empirical piece is an Interpretative Phenomenological Analysis (IPA) of how therapists working with clients with long-term conditions make sense of their clients' experiences and their therapeutic work together.
Introduction to the Portfolio

This portfolio contains a selection of papers and research reports written over the course of my training, which have been included in order to illustrate how my academic thinking, clinical practice and research skills have developed throughout the course. For this purpose, the portfolio has been organised into three main sections: academic, therapeutic practice and research. In this introduction, I hope to provide the reader with an overview of the material that will be presented and with a sense of myself as a person and how my academic, clinical and research interests have shaped my personal and professional development as a counselling psychologist. In order to put myself in context, I would like to begin by proving a brief account of my background and why I was drawn to Counselling Psychology.

My background

I was born and raised in Spain with three siblings in a multicultural family. Apparently, when I was about eight years old, I declared that I wanted to be a child psychologist, which was an unexpected announcement as there are no therapists in my family and I had previously wanted to be a princess and a private detective. Since as far back as I can remember, I have enjoyed helping people and animals in distress. My parents and siblings are very caring people who go out of their way to help others and growing up in such a family culture shaped my sense of purpose and responsibility towards others. Additionally, I have always been fascinated by people and wanted to understand how people think, feel and behave and how people come to be a certain way and why. I have always loved reading psychology and self-help books and having deep conversations with others, exploring ‘big issues’ like love, death, life, fate,... In addition to having a multicultural family, I attended an international school where I became acquainted with numerous different nationalities, cultures and religions. Growing up in such a rich cultural environment, and subsequently living in three other countries, stimulated my curiosity and my sensitivity to cultural differences and how they shape people’s lifestyles, perspectives and relationships.
Although I was a predominantly happy child, I also had a number of difficult experiences including: severe asthma and allergies, which meant I spent a lot of time in hospital; experiencing interpersonal trauma; and a friend’s suicide when I was fourteen which precipitated a long period of struggle, depression and self-destructiveness. In desperation, my parents sought professional help and at the age of fourteen I found myself in therapy for the first time.

Over the next few years I saw a number of therapists using different approaches (integrative, psychodynamic and CBT), including a Psychiatrist who believed that medication was the answer to all my problems. Although initially I did not see the point of therapy and I didn’t believe that things could improve, I gradually realised that the ‘impossible’ had happened. I had gradually started feeling stronger and better equipped to deal with life and therapy had played a crucial role. My personal experience of the power of therapy as a vehicle for insight, restoration and transformation brought me hope and strengthened my resolve to become a therapist. I looked up psychology courses at different universities and began the application process. However, certain members of my family made a compelling case for studying Business Management instead. I tried it, I hated it and I swapped to Marketing and Public Relations in an attempt to compromise by doing something business-related but with psychological components. I didn’t love it but it was alright and when I completed my studies I joined the workforce. After a year of dragging myself out of bed to carry out a ‘meaningless’ job, I decided that life was too short not to do what I loved and I returned to university to do a BSc in Psychology (at last!).

Why I chose Counselling Psychology

During my undergraduate placement year, I was able to get individual and group experience in a hospital and an inner city school in Boston, working with children who had health and behavioural difficulties respectively. I also gained experience as a research assistant and was able to engage in interesting research which was subsequently published. I realised that I was passionate about both research and
practice and so, during my final year, I explored postgraduate training possibilities hoping to find something that would enable me to develop as a researcher and a practitioner.

I was particularly drawn to Counselling Psychology because it covered the three main therapeutic models which I was interested in. Since I had personally experienced a range of modalities and had first-hand experience of the similarities and differences and the strengths and weaknesses of different approaches, I felt that a grounding in all three modalities and developing the ability to evaluate and critique different approaches provided the most solid and sound foundation for an aspiring practitioner. Having experienced a range of relationships, some destructive and some nourishing, I was also very aware of the importance of relationships (both therapeutic and non-therapeutic) in shaping our way of being and relating to others and to ourselves and I liked Counselling Psychology's relational stance and its emphasis on the therapeutic relationship. Similarly, I was inspired by Counselling Psychology's criticism of accounts of human suffering which locate issues intra-psychically, neglecting the wider contexts and relational networks within which individuals are embedded. I was also encouraged by the focus on wellbeing and on the phenomenological endeavour of trying to understand how different people make sense of their experiences and suffering and how they manage them. Finally, I valued the required engagement in personal therapy, since I have always been uncomfortable with the notion of therapists who have not/will not engage in therapy and I feel that it is congruent with Counselling Psychology's reflective, exploratory, relational and non-pathologising values.

The Academic Dossier

The academic dossier is comprised of three essays which I wrote over the course of my doctorate. Each essay was taken as an opportunity to research and develop my understanding and thinking around the clinical and theoretical issues I was grappling with at the time.
The first essay, entitled ‘Review of Sanders, Frankland & Wilkins’ chapter on “Making Contact”’, is a review of a chapter which focuses on the topic of psychological contact. It was written when I was just beginning my first placement and I was eager to familiarise myself with person-centred literature in order to inform my practice and allay my anxiety. I decided to explore psychological contact because it seemed fundamental to therapy and yet, there was a dearth of literature on it compared with the other core conditions. Additionally, while I felt that I understood the other conditions, I felt that psychological contact was somehow more elusive and hard to describe. Therefore, I set out to broaden my theoretical understanding of psychological contact and its implications for therapeutic practice, providing some instances from my previous experience. The essay describes different types of psychological contact and its dynamic and multi-dimensional nature. Additionally, the essay discusses contact from a range of theoretical perspectives and outlines different ways of establishing and maintaining contact with different client groups.

The second essay, entitled ‘Working psychodynamically with a client experiencing grief and Generalised Anxiety Disorder (GAD)’, was written at the beginning of my second year when I was beginning my placement at the children’s centre. The task of the essay was to choose between a number of ‘diagnoses’ (i.e. Borderline Personality, Depression, Schizophrenia or Anxiety) and to describe how one would work psychodynamically with this diagnosis. It was suggested that we base the essay on a client whom we had worked with previously and since I had just begun my placement, and the children I worked with did not have specific ‘diagnoses’, the essay is not based on a child client but on an adult client from my previous placement. I chose a client on whom I had previously based a process report, because I thought it would be interesting to compare person-centred and psychodynamic conceptualisations of the client. (Although this was not discussed explicitly in the essay, the process report is available to the reader). I also wanted the preparatory reading for this essay to help inform my thinking and therapeutic work with children. Therefore, I decided to focus on Klein’s theory on primitive defences. In the essay, I outline Klein’s developmental positions and their relation to anxiety and mourning and the processes that the ego
must undergo in order to overcome these states, contrasting some elements with Freud’s paper on Mourning and Melancholia (1917). I then describe how I would draw from Klein’s theory in order to conceptualise the client’s presenting issues and to identify areas of focus for therapeutic work.

The third essay, entitled ‘What are the implications of the differences between traditional CBT and ACT when working with clients with chronic pain?’, was written as I was starting out my final year placement in a specialist service dedicated to working with clients with long-term health conditions. While the third year focused on CBT, the model predominantly used at my placement was ACT. I was looking forward to learning both models but also felt quite daunted at the prospect since at that stage I knew very little about either. Therefore, I felt that I needed to get a clear sense of the similarities and differences between ACT and CBT as soon as possible in order to reduce my confusion and to be able to use them effectively with my clients. In the essay, I describe traditional CBT and ACT, outlining the differences between, the benefits and challenges of each and their relevance to working psychotherapeutically with clients with chronic pain. I conclude by arguing that an ACT model may prove valuable in cases where a traditional CBT approach is limited or has become stuck and that combining ACT and CBT techniques when working with clients with chronic pain more effectively addresses clients’ needs, by supporting them in changing what they can change and accepting what they cannot change.

The Therapeutic Practice Dossier

The therapeutic practice dossier provides an overview of my clinical and professional development throughout my training. I describe the types of service, range of clients, therapeutic orientations and additional responsibilities and professional activities I engaged in across the different placements I trained in. The first was in a university counselling service which offered short and mid-term therapy predominantly to young adults with a range of presenting issues. The second was with a charity which provided psychodynamic and child-centred mid- and long-term therapy to child and
adolescent victims of domestic violence. In my final placement, I worked in secondary care with a specialist NHS team which provided CBT and ACT to people with long-term health conditions. I worked both in the specialist department offering individual short and mid-term therapy and in two different departments at an acute hospital where I worked with individuals and also co-facilitated ACT-based pain management groups. This dossier also includes my final clinical paper, which describes my personal and professional development as a counselling psychologist throughout the course.

The Research Dossier

This final dossier is comprised of a literature review and two qualitative research studies. My interest in the topic of hope developed as a result of numerous experiences which sparked my curiosity regarding hope and hopelessness. For instance, I had personally experienced hope and hopelessness during my 'depression' and subsequent 'recovery' and several people close to me had struggled with long-term and recurring depression and other psychological difficulties. In addition, two of my best friends and my sister were diagnosed with life-changing long-term conditions. I was intrigued by how different people responded to their difficulties, some thriving while others fell into despair, and what helped people to get through the 'ups and downs' they faced. Whether discussing physical or psychological issues, hope and hopelessness were recurring themes and hope seemed a crucial aspect of wellbeing and motivation. Therefore, I decided that I wanted to explore the literature on hope in order to further my theoretical understanding of hope and its potential role and uses in therapeutic practice. In the two ensuing empirical studies, I decided to narrow my focus to long-term health conditions, in order to shed some light on the experiences of people diagnosed with chronic conditions and of practitioners working with this client population.

My literature review entitled 'Uses of hope in counselling and psychotherapeutic practice: a critical review' aimed to explore and critique the existing literature
regarding different conceptualisations of ‘hope’ and their implications for practice. The review provides a discussion of the different perspectives on hope, including hope as an emotional, cognitive, behavioural, relational, and developmental or temporal phenomenon. Subsequently, I outline different models and conceptualisations of hope, followed by different perspectives on working with hope therapeutically and the relevance of hope/hopelessness to therapy. Finally, I discuss the implications for practice and identify possible areas for future research.

My first empirical piece was entitled ‘Living with chronic illness: A Grounded Theory study of adapting to chronic illness when diagnosed when young’, and explored the experiences of people who had been diagnosed with a long-term illness when they were young. I found the process of interviewing participants and exploring the transcripts fascinating. I also felt that listening to and transcribing interviews, a bit like writing process reports and verbatims, really helped me to become aware of the co-construction of interactions i.e. what is/isn’t asked, how things are said, what is missed etc. Based on the findings, I proposed a theoretical framework with which to understand people’s experiences of chronic illness as an iterative and continuous process of adapting to a new normal. This process involves adapting to a new body, a new life and seeking information. Findings from this study contribute towards a richer understanding of the experiences of people who were diagnosed when they were young and provide new insights into how illness influences their identity and development. Finally, I discuss the implications of these findings for clinical practice. Following on from my previous study, I was interested in exploring accounts of chronic illness from therapist’s perspectives. Therefore, for my second empirical piece, entitled ‘Closing the gap’: Personal meanings among psychotherapists working with clients with long-term health conditions’, I adopted an Interpretative Phenomenological Analysis approach to explore how practitioners made sense of clients’ long-term conditions. I found that when I began my second empirical piece, I had progressed as a researcher. I was more structured and organised. I set out with a clearer sense of how to do things and had developed a more systematic approach which really helped to contain the ‘messiness’ which slightly overwhelmed me during
my first piece and to remain focused on the analysis. The study found that participants anchored their understanding of their clients' experiences by drawing similarities between themselves and their clients and distinctions with other client groups. I then discuss the implications of the similarities and distinctions described by participants for the therapeutic relationship, process and outcome and for the therapist's own experience.
ACADEMIC DOSSIER
Introduction to the Academic Dossier

This dossier includes three theoretical pieces which I wrote over the course of my training. The first essay reviews and critiques a book chapter entitled “Making contact” which explores the concept of psychological contact. The essay describes different types of psychological contact, discusses contact from a range of theoretical perspectives and outlines different ways of establishing and maintaining contact with different client groups. The second essay describes working psychodynamically with a client experiencing grief and Generalised Anxiety Disorder. I describe how I would draw from Klein’s theory of primitive defences and their relation to anxiety and mourning in order to conceptualise the client’s presenting issues and to identify areas of focus for therapeutic work. Finally, the third essay outlines the differences between traditional CBT and ACT, the benefits and challenges of each and their relevance to working psychotherapeutically with clients with chronic pain.
Introduction

Psychological contact is the first of Rogers' necessary and sufficient conditions for therapeutic change. Rogers highlighted that it is such a simple, yet essential condition that 'perhaps it should be labelled an assumption or a precondition in order to set it apart' (Rogers, 1957, p. 96), as without it, the other conditions would be meaningless. Indeed, psychological contact is often taken for granted in the therapeutic relationship, which accounts for the remarkable dearth of material on this condition, in contrast to the wealth of material there is on the other conditions. Similarly, a comprehensive and unambiguous definition for this condition is quite rare in the literature, in spite of being considered the fundamental basis for all the other conditions (Rogers, 1957). Considering that psychological contact is the bedrock of therapeutic relationships, it seems essential that trainees and therapists have a clear idea of what psychological contact is. A clear understanding of the importance and nature of psychological contact would avoid trainees taking it for granted, thereby neglecting or misunderstanding it and ultimately rendering a disservice to their clients.

The nature of psychological contact

This chapter is useful for counselling trainees because it provides a good overview of psychological contact, and unpacks several concepts which are relevant to this condition. It begins by offering a simple and clear definition of psychological contact, similar to Rogers' (1957) own, based on the concept of awareness. It stems from Rogers' hypothesis that constructive personality change may only occur in the context
of a relationship (Rogers, 1957). A minimum awareness of each other is necessary for this relationship to be possible and thus, a key aspect of psychological contact is that individuals must have some awareness of each other.

Having provided a basic definition of psychological contact as an awareness of each other, the chapter explores the nature of psychological contact, breaking it down into its constituent parts and highlighting different aspects of it. Firstly, contact is described as a relationship. The authors make a useful reference to the fact that Rogers had initially named this condition ‘relationship’, but changed it to avoid misunderstandings (Rogers, 1959). In this way the authors draw attention to the paradoxical nature of this condition, which encompasses both basic awareness and complex relationship. This section poses a series of important questions which helped me to think about contact-as-relationship and what this entails in terms of contact types, dynamics and processes. This helped to increase my awareness of how I, as a person and therapist, conceptualise contact and recognise its presence or absence. Viewing psychological contact in terms of a relationship helped me to understand that, just like relationships, it is variable and constantly in process. Further reading around the topic lead me to conclude that awareness of one another may be necessary but not sufficient to constitute psychological contact. For instance, Mearns and Cooper (2005) highlight that loneliness is not about the physical presence of others, or an awareness of others. Indeed, one can feel lonely in a crowd or in the company of a friend or partner. van Baarsen, Snijders, Smit, and van Duijn, (2001) distinguish between emotional and social loneliness, again providing evidence that there is more to loneliness than the presence or absence of others: it is about feeling a lack of meaningful contact. Similarly, it seems that there is more to psychological contact than awareness, and it involves a subjective feeling of connecting with someone at some level. Hence, the difficulty in measuring psychological contact. The authors mention that because psychological contact is more of a feeling than a behaviour, it is difficult to come up with specific behavioural indices with which to measure it.
Different theoretical perspectives regarding the nature of psychological contact are presented (i.e. that contact is something that is either present or not, that it can be viewed as a continuum between no contact and full contact, or it is variable and dynamic). By outlining a range of theoretical perspectives, and including an activity inviting the reader to reflect on one's own thoughts regarding contact, it stimulated me to think about my personal view on the nature of psychological contact. As a trainee, I found this very useful, as it seems essential to have a clear awareness of the changing nature of contact in the therapeutic relationship, and how to be attuned to it. This section helped me to conclude that, like all relationships, psychological contact is a dynamic, fluctuating and complex phenomenon. Just as individuals are constantly in process, so necessarily the psychological contact that occurs between them is constantly in process.

Types of contact

It is then argued that there are many types of contact, ranging from simple everyday interactions towards more sophisticated types of contact, such as those that are required for a therapeutic relationship. It was useful that different types of contact were mentioned (e.g. physical, cognitive, emotional, presence) as it enabled me to think of contact in a multidimensional way. However, as a trainee, I was left wondering how I could identify and work with the different types of contact. More depth of description would have been useful in order to achieve a more concrete understanding of contact types. This could help trainees to identify, establish and manage different types of contact in therapy. Cameron (2003) explains that what is important is to realise that there are different degrees of psychological contact, and that this is what makes a difference to the nature of the therapeutic process and outcome. She distinguishes between fundamental (i.e. basic and cognitive contact) and 'deeper' contact (i.e. emotional and subtle contact) and explores some of the potential difficulties in establishing contact. Importantly, she notes that difficulties may arise from both the client and the therapist. For instance, cognitive contact involves sharing meanings and this can be hindered or facilitated by the language used by clients and
therapists. For example, some clients may feel more at ease with less formal language while others may feel offended. Similarly, our clients’ form of speech may include references to particular sub-cultures and slang which we cannot understand. Being mindful of establishing contact at a cognitive level (e.g. attitudes, values and beliefs) is essential to understanding our clients’ frame of reference and how they construct meaning.

Similarly, emotional contact is essential in order to fully understand the client’s experience and feel empathy. Without emotional contact, Cameron (2003) argues, the connection stays on the surface and focuses on words. For example, I had a client with whom I connected cognitively, but I noticed that she would shut down when it came to emotional content. This gave me insight into how she was cut off from her emotions and avoided them, which was impacting upon her relationships with others. Had I not been aware of the different types of contact, I may have overlooked the fact that although we connected in some ways, my client was specifically ‘blocking’ emotional contact. In addition, therapists must endeavour to maintain emotional contact with themselves (congruence), and be mindful of when and why they withdraw emotionally in therapy, as this is essential to understanding the therapeutic relationship.

**Psychological contact as a two-way road**

The authors introduce the concept of consent and reciprocity in psychological contact, highlighting that, as in any relationship, contact is a two-way process and is not something that can be forced upon someone. If the client does not wish to make contact, or wishes to shut the therapist out, therapy cannot happen. When clients do not want therapy, or dislike the therapist, they will resist letting the therapist into their psychological landscape, as it would feel like a threat or an unwelcome intrusion. The issue of one-way contact again illustrates how complex psychological contact can be, and that it involves more than a simple awareness of each other or sharing a physical space. It also requires a willingness or ability to open up (lower one’s defences), in
order to allow contact to occur. Clearly, for therapeutic purposes, psychological contact needs to be more than simple awareness of one another. For example, I worked as a counsellor at a school with a five-year old girl from a shelter who was traumatised and withdrawn. For a couple of weeks before starting therapy, I visited her at recess and in the lunchroom so that she would get used to me and hopefully feel less threatened by me. Initially, she would not look at me or speak to me and would freeze if I came close to her. However, I noticed that she watched me interacting with the other children. She was studying me and deciding whether to ‘let me in or not’. For several weeks, she remained withdrawn, tense and uncommunicative. I would tell her stories, make puzzles and play until gradually she began to join me, although she still wouldn’t speak or make much eye contact. I would talk throughout the sessions, commenting on what I was doing and what she was doing. Gradually, she began joining me in making puzzles and drawing, even smiling and laughing. One day, she started commenting on our puzzles and telling me about life at the shelter, the people she knew, and what she did there. She had finally decided to let me in. Without her permission, there was no chance of making psychological contact.

Reciprocity is crucial, and there are other potential obstacles, other than a lack of consent or ability to engage, which were not explicitly covered in the chapter. Namely, obstacles to contact coming from the therapist rather than the client. For instance, the therapist’s lack of congruence or preoccupation with feelings of inadequacy, lack of self-acceptance or guilt (Mearns & Thorne, 2000), or when feeling uncomfortable, threatened, or angry (Cameron, 2003), may interfere with the therapist’s ability to be psychologically available to the client. Similarly, contact may fluctuate depending on the degree to which the therapist and client feel tired, ill, distracted, or need to disconnect from difficult material.

Different means of establishing contact

The authors mention that contact can be established by means of communication media. This is an interesting point, especially in the era of modern technology. Indeed
Barak, Hen, Boniel-Nissim & Shapira (2008) examined the effectiveness of various Internet-based forms of psychotherapy and concluded that they were on a par with traditional face-to-face therapy, which illustrates the fact that psychological contact does not require physical presence.

The chapter also challenges the notion that the only possible, beneficial and desirable way of establishing, maintaining and enhancing contact and relating therapeutically with a client involves engaging in one-to-one ‘talking therapy’, in a room and for a specific duration. The authors outline therapies that deviate from the established norm, offering different ways of creating psychological contact and expanding the therapeutic environment and the length and breadth of contact. This is helpful for trainees because it challenges stereotypical notions of psychological contact and emphasises the need to develop a less restrictive conceptualisation of human connectedness, in order to incorporate alternative ways of establishing psychological contact. An example of this is Wilderness Therapy, which provides an alternative for youth and young adults who do not engage with conventional therapy (e.g. Opensky Wilderness Therapy, 2009).

Examples of how concepts similar to psychological contact exist in other theoretical frameworks under different terms (e.g. rapport or interactive communications) are provided, to illustrate the importance of the concept across theoretical perspectives. It is argued that psychological contact is essential to any therapeutic process because it enables therapists to sense what is not being verbalised or expressed, and to sense fluctuations in the therapeutic relationship.

**Presence**

The authors also introduce a deeper, more ethereal, dimension to psychological contact. Firstly, psychological contact is described in terms of sharing a mutual awareness of the present moment with the client. Being psychologically available requires being in the present, as opposed to being preoccupied with the past and the
future and not fully available for contact. The authors also discuss a ‘deeper’ type of contact that Rogers (1986) referred to as ‘presence’. While Rogers initially described psychological contact in terms of simple awareness, he eventually introduced the concept of a more metaphysical type of contact where his “inner spirit reached out and touched the spirit of the other” leading to “profound growth and healing” (Rogers, 1986, as cited in Kirschenbaum and Henderson, 1990, p. 137). Other authors have also referred to a more complex, deep, or spiritual type of contact in therapy (e.g. Cameron’s (2003) subtle or instinctive contact and Mearns and Cooper’s (2005) relational depth), illustrating how contact ranges from basic awareness, to a ‘deeper’ or more meaningful or intimate connection with another.

Pre-Therapy

The issue of clients who cannot engage in psychological contact, whether because of a degenerative illness, psychosis, learning disability, trauma or special needs, is also addressed. The authors outline Garry Prouty’s (2001) method for creating and maintaining psychological contact with contact-impaired clients. Pre-therapy aims to increase the client’s awareness of self, others and the world, which is the first ingredient in establishing psychological contact and developing a therapeutic relationship. The effectiveness of pre-therapy with various contact-impaired populations is strongly supported by research. I would have liked to know more about this because it seems that Prouty is one of the few to actually conceptually define and operationalise psychological contact, defined in terms of therapist’s work (contact reflections), client’s internal process (contact functions to establish awareness of the world, one’s feelings and communication with others) and behaviour indices (contact behaviours) (Prouty, 2001). The authors also outline theory arguing that contact-impaired people move from full lack of contact to full contact, once again illustrating the dynamic nature of contact even in extreme cases.

I found this section helpful in illustrating that psychological contact is an essential prerequisite for therapy, that it can’t be assumed to just occur with all types of client
and that, at its most basic level, it requires an awareness of oneself, others and the world. Some have argued that the six conditions are not necessary because therapeutic change can happen without them (e.g. reading a self-help book, or chatting with an non-empathetic stranger), but that they are usually sufficient to provide a context for positive change (e.g. Mearns & Thorne, 2000). However, the fact that contact-impaired people require pre-therapy illustrates that psychological contact is a condition which is necessary for positive psychological change to occur.

Although designed for contact-impaired clients, the theory is conceptually linked to work with ‘normally functioning’ clients, as the aim is to increase self-awareness, other awareness and awareness of one’s environment by focusing on things like the here-and-now, body language (pre-expressive communication), empathy and verbal reflection (although in pre-therapy this is done word-for-word) (Prouty, 2001). The difference between the ways of establishing and maintaining contact in pre-therapy work and in therapeutic work appears to lie mainly in the degree of sophistication of the contact behaviours and reflections (Clarke, 2005; Prouty, 2001), which are adapted to the level of awareness of the client. Indeed, Cameron (2003) describes contact reflections as more of an expression of a receptive attitude, or a person-centred way of being, than a technique. She argues that ‘contact reflections’ are just another way of trying to understand and relate with the person. In other words, pre-therapy reflects a holistic view of clients (i.e. being interested in their words, face, body, environment, and processes) and a willingness to meet clients where they are at and guide them out of their isolation to a place where they can engage in meaningful contact and therapeutic change.

**Contact in practice**

In the final section, the authors address the relevance of psychological contact to counselling practice. They highlight the importance of being aware of the different types of contact and the constant fluctuation between no contact and full contact, as these impact directly upon the therapy. Therefore, trainees must be aware of how to
create, maintain and gauge contact. Additionally, they explain that the contact elements described by Prouty (i.e. awareness of self, others and a common understanding of the situation), are also present in less extreme situations and so, are still relevant when counselling 'normally functioning' clients. They explain that some people can only engage in shallow contact because they are tired, distressed, or on drugs or alcohol. Therefore, they are not fully conscious and thus are unable to engage beyond superficial, intermittent and usually meaningless contact. Since therapists will be faced with clients in this condition, the authors emphasise that we must explicitly learn to establish, maintain and strengthen contact and to be aware of its fluctuations in intensity and continuity. Finally, the authors stress that psychological contact is essential and that although it may sound simple, it is complex and multidimensional, ranging from basic awareness of another to a deep connection.

Conclusion

In sum, psychological contact is a condition which is hard to define and describe. This chapter provides a thorough overview of the concept, highlighting and clearly conveying key relevant aspects. In terms of content, the authors provide a lucid definition and a range of theoretical perspectives, making links to relevant research where possible. The reader is invited to reflect on different types of psychological contact, its dynamic nature and different ways of establishing and maintaining contact with different client groups. This was particularly helpful for me in terms of developing a clear understanding of psychological contact with which to guide my practice. However, more depth on certain concepts and how they relate specifically to practice would have been useful.
References


Essay 2: Working psychodynamically with a client experiencing grief and Generalised Anxiety Disorder (GAD).

In this paper I describe how I would work with a client in mourning diagnosed with Generalised Anxiety Disorder (GAD). After describing the client's presenting issues and background, I outline Klein's theory on primitive defences and their relation to anxiety and mourning, contrasting some elements with Freud's paper on Mourning and Melancholia (1917) and some contemporary theory. I then describe how I would draw from these theories to conceptualise the client's presenting issues and to create a theoretical framework from which to work with the client therapeutically.

The client

Miss P\(^1\) was diagnosed with GAD a couple of months before starting therapy. The DSMIV (American Psychiatric Association, 2000) describes GAD as experiencing excessive anxiety and worry about a variety of events and situations for a minimum of six months. The anxiety is characterised by at least three of the following symptoms: feeling wound-up, tense, or restless; easily becoming fatigued or worn-out; concentration problems; irritability; significant tension in muscles; and difficulty with sleep. In addition, the individual must find the anxiety and worry significantly difficult to control and cope with.

Miss P was in the second year of a biology course. She was pretty, soft-spoken, smiling, and polite. Miss P talked openly about herself and her experiences, including difficult ones, and usually wept during the sessions, which she tended to apologise for. She said that she has not made any close friends at university and reported feeling homesick and relying on her friends and family from home for support.

\(^1\) Identifying information has been changed/omitted in this essay to ensure anonymity.
Following her father’s sudden death from a stroke a year prior to starting therapy, Miss P started worrying and getting into panic states about her loved ones suddenly dying. She felt that she was struggling to come to terms with his death and that her anxiety was sabotaging her studies and close relationships. Miss P felt that small things which previously had not upset her now triggered her anxiety and that she couldn’t cope with everyday stresses. She also worried constantly that she would drive her loved ones away by ‘burdening’ them with her problems.

Background

Miss P’s parents divorced when she was a young teenager, which she experienced as unexpected and quite traumatic. Growing up, she was reportedly unaware that her parents were having problems with their relationship, so when they announced that they were getting divorced, she was completely shocked. Additionally, they shared the house throughout the divorce and the atmosphere at home apparently became very hostile, especially with regard to the mother, who would try to persuade the children to take her side, and “pushed” them away when they didn’t. In therapy, Miss P expressed resenting her mother for withdrawing into herself and not being available to her at that difficult time. The mother was reportedly furious with the father and threatened to move away and take the children with her after the divorce. Miss P constantly felt torn between her parents and distressed about the fighting and felt that her world had been turned upside down. Because Miss P was older than her sister, when it came to deciding which parent they would live with, it was her responsibility to choose. She felt that her father had been kind and supportive while her mother had been manipulative and selfish, and Miss P feared that her mother really would not allow them to see their father, whom Miss P felt very close to. Therefore, Miss P chose to live with their father. After the divorce, Miss P and her sister became estranged from their mother. Apparently they attempted to stay in touch initially, but the mother was very bitter about them living with their father and the encounters were very disagreeable and emotionally charged. In the end, both sides desisted from
attempting any more encounters and Miss P and her sister did not see their mother for
several years, until a few months after the father’s death.

Shortly before the father’s death, Miss P, her sister and father and the father’s partner
and son had moved into a new house together. Apparently, after the father’s death his
partner initially said that they could all stay together as a family. However, tension and
conflict between them grew and a few months later, following an argument, the
partner “kicked them out” by leaving Miss P’s and her sister’s things in front of the
house while they were out and changing the locks. Furthermore, the partner refused
any more contact with Miss P and her sister and kept the father’s ashes, refusing to
place them somewhere where the family could visit them, and kept all of the father’s
possessions, except for a bag of old things which she gave to Miss P.

Miss P felt completely shocked by her father’s sudden death but felt that she had to
“be strong” and “hold it together” for her sister and family. Because of this and the
busy period that followed, she felt that she didn’t get a proper chance to mourn at the
time and felt sadder now than she did at the time.

When Miss P and her sister got “kicked out” of the father’s house, Miss P had no
choice but to contact their mother. Miss P reported that her relationship with her
mother improved significantly, that she now felt very close to her, that she was very
supportive and that reconnecting with her was the only good thing to have come from
her father’s death.

Formulation and therapy

Klein postulated that infants' development, from primitive part-object relationships
towards relating with integrated and external objects, involved the unconscious
working through of the paranoid-schizoid and depressive positions (Klein, 1935).
These positions are associated with different anxieties (persecutory and depressive)
and defence mechanisms and unlike developmental stages, which are worked through sequentially, developmental positions can be returned to (Young, 2000b).

The paranoid-schizoid position precedes the depressive position and is characterised by persecutory anxiety and a fear of annihilation, which arise from the death instinct operating from within (Klein, 1946). While Freud viewed anxiety as arising from fear of castration and of the loss of the object, Klein argued that the death instinct generated a fear of annihilation in the primitive ego which caused the ego to project the death instinct outwards to defend itself against anxiety (Klein, 1946). The paranoid-schizoid position is characterised by the early ego’s use of splitting, projection, projective identification and introjection as defences against the fear of disintegration and its own aggression (Klein, 1946). Splitting is one of the earliest ego defences against anxiety (Segal, 1979) and enables the child to protect the ‘good’ by keeping the ‘good’ and the ‘bad’ separate. Klein (1946) adds that splitting may result in the idealisation of the ‘good’ object, as any negative aspects such as frustration and persecution are split off and denied. The ego then projects the ‘bad’ in order to protect itself against anxiety (Klein, 1946). However, the outward projection of negative split-off aspects onto an object produces a ‘bad’ external object, which is then feared and experienced as persecutory. Conversely, the ego ideal and ‘good’ parts can be projected into an external object to protect them from destructive internal objects. These external objects, which are consequently experienced as ‘good’, are loved and idealised, whereas the ‘bad’ objects are hated. Both ‘bad’ and ‘good’ external objects can then in turn be introjected. Klein (1946) argues that the introjection of a ‘good’ object is essential for normal development, and highlights the role of the internalised ideal object as a defence against persecutory anxiety and the disintegration of the ego. On the other hand, introjected ‘bad’ objects are experienced as punishing and persecutory. For instance, a harsh superego arises from the introjection of ‘bad’ objects (Segal, 1979). While in the paranoid-schizoid position splitting results in a weakened and fragmented ego, the depressive position results in the integration of ‘good’ and ‘bad’ and internal and external objects.
The depressive position is associated with depressive anxiety and is characterised primarily by a fear of persecution by ‘bad’ objects and a pining for loved objects (Klein, 1940). In this position, the objects, which had been split into ‘good’ and ‘bad’ part objects in the paranoid-schizoid position, are integrated into a unified whole (Klein, 1935). This integration entails the realisation that the ‘good’ objects are not entirely good and that the ‘bad’ objects are not entirely bad (Klein, 1935). As the objects become integrated, the infant realises that the loved and hated objects are one and the same and the ambivalent feelings experienced towards the object produce a deep conflict in the infant’s mind (Klein, 1935). Indeed, this realisation is accompanied by feelings of anxiety, loss, sadness and guilt, as well as the infant’s developing capacity to shift its concern from the self to others, as the infant becomes aware that the aggressive impulses which it directed towards the ‘bad’ object may have damaged the loved object which it forms part of (Klein, 1940). Consequently, the infant experiences an unconscious wish to repair the damage caused by its attacks on the ‘good’ object (Klein, 1935). It also begins to mourn the loss of the ideal object and the love, goodness and security it represented for the infant (Klein, 1940), a process which is considered vital to the infant’s emotional and intellectual development (Klein, 1946). The central task for the ego in the depressive position is to establish an integrated and good enough internal object, a process which is contingent on positive parenting from the mother.

**Klein’s developmental positions, mourning and the therapeutic process**

Klein (1940) argues that the loss of a loved object in adulthood revives the conflicts of the depressive position and that the states of mind, feelings and processes that the child and the mourning adult undergo are similar and must be overcome in a similar way. In other words, Miss P would benefit from working through the feelings of loss, remorse, conflict between love and hate, testing of reality and anxieties over the death of the internal and external loved objects, which are characteristic of infants in the depressive position and adult mourners (Klein, 1940).
Additionally, Klein (1935, 1940) argues that the task of the mourner is more easily and swiftly accomplished if a ‘good’ mother has been internalised in early life, whereas abnormal mourning occurs when there has been a failure in early childhood to establish ‘good’ internal objects and a secure inner world. Freud (1917) also distinguishes between ‘normal’ and ‘abnormal’ mourning with regard to experiencing loss internally or externally, arguing that in mourning it is the world that becomes impoverished while in melancholia it is the ego. In terms of therapeutic work, Klein (1940) sees therapy as helping the client to internalise a ‘good’ object, process grief, and restore balance and security in the client’s inner world. In order to do so, the therapist must understand the complex inner world of the client, identifying and working through early anxiety situations and object relations, through constant interpretation and tracing the transference to past experiences (Klein, 1940). In this respect, Miss P’s experiences of her mother as unavailable, punitive and manipulative, the divorce, the estrangement, the father’s sudden death, the ex-partner ‘kicking’ her out and keeping the father’s ashes and belongings, and moving to university, among other experiences, provoked a sense of loss, chaos and inner disintegration which needed to be processed therapeutically.

Freud (1917) describes mourning as a process whereby reality-testing confirms the loss of the loved object and gradually the libido attached to the object is withdrawn until the ego is no longer bound by the object. However, Klein (1940) argues that the suffering produced by the loss of the actual object is exacerbated by internal fantasies of having lost the loved internal objects as well, leaving only ‘bad’ internal objects and the threat of disintegration. Therefore, she added, the internal ‘good’ objects, which are also experienced as lost by the unconscious during mourning, must be reinstated as well, in order to rebuild the inner world. Indeed, a theme that emerged over the course of Miss P’s therapy seemed to allude to her fear of losing not only her real father but her internalised father. She was terrified by how much she had forgotten about him already and feared that she would completely forget him if she stopped mourning, unconsciously equating letting go of her sadness with losing her memory of her father. A poignant example of Miss P’s inner state of disintegration and
her need to reinstate her loved object in her inner world occurred when Miss P expressed that she had a large bag with her father’s old things which his ex-partner had given to her. Miss P had been driving around for months with the bag in her car because she couldn’t bear to look at it yet or to contemplate giving his things to charity or throwing them out. Miss P had not yet been able to introject her father and fantasised that in throwing away his things, she would be throwing him away and losing him. Therefore, she needed to “carry him around” with her wherever she went (in her boot) in an unconscious attempt to restore him and keep him safe (Klein, 1940).

The dynamics in Miss P’s relationship with her parents can be conceptualised in terms of a movement from a paranoid-schizoid to a depressive position. Her experience of her parents was split, with her mother representing the ‘bad’, rejecting and punitive object and her father representing the idealised, nurturing and loved object. Perhaps in this way, Miss P could protect the ‘good’ object and manage the anxiety of being torn and made to choose between her parents. However, the death or loss of a loved object often produces hatred towards the object for having left the mourner (Segal, 1979). Klein (1940) argues that when feelings of hate towards the loved object emerge, the loved object becomes a persecutor, which disrupts the mourner’s belief in the ‘good’ object and the relief and reassurance the mourner derives from idealising it. When this occurs, splitting as a defence against anxiety is no longer as effective and it is only by gradually regaining trust in external objects that the mourner can regain trust in the loved object and can begin to accept that the object was not perfect, while maintaining love for the object and not fearing being persecuted by it (Klein, 1940). Similarly, it appears that following her father’s death, Miss P began to experience her mother from a more depressive position, triggering feelings of guilt and grief regarding the ‘damage’ she had inflicted on the ‘bad’ object and motivating her to restore and repair the damage. However, Miss P could not yet tolerate her ambivalent and ‘unacceptable’ feelings towards her mother and this conflict generated much anxiety in her. Additionally, her fear of her loved ones suddenly dying may be explained in terms of the persecutory fears that arise in the depressive position involving fears of
being punished and robbed by internal ‘bad’ objects (Klein, 1935). Alternatively, Miss P’s aggressive feelings towards her parents may have been projected outwards to protect her loved internal object, resulting in fears that the ‘world’ would punish and rob her by killing her loved ones.

**Therapeutic focus**

In terms of therapeutic work, advances in the integration of the ego often result from interpretations regarding the causes of splitting (Klein, 1946). Therapeutic work with Miss P would involve working in the transference and connecting with the past to bring to consciousness the anxiety situations which drive the ego to regress to the paranoid-schizoid position (Klein, 1946). Klein (1946) argues that the integration arising from such interpretations results in waves of depression and anxiety, which ultimately reduce splitting, strengthen the ego, enable a shift into the depressive position and impact upon object relations (Klein, 1946). However, while Klein believed that countertransference interfered with analysis, other analysts would argue that rich interpretations arise from the therapist’s awareness of counter-transferential feelings, which represent the process of projective identification between therapist and client (Young, 2000b). Therefore they would argue that an interrogation of the countertransference (Young, 2000b) would contribute towards achieving the aim of every interpretation, which is to help the client to “take back the projections” (Brennan-Pick, 1985, p. 37), thereby shifting from the paranoid-schizoid to the depressive position.

**Post-Kleinian theory**

While Klein argued that the depressive position was revived during mourning, some post-Kleinians argue that the positions in fact represent basic and permanent modes of feeling between which people oscillate (Young, 2000a) and that the depressive position is never transcended but must be worked through with each loss or change experienced (Britton, 1992). Young (2000a) outlines post-Kleinian theory which
posits that, considering that all individuals oscillate between positions, it would be a matter of the degree to which the anxieties and defences of each position are present and of the individual’s ability to navigate the positions that would determine the level of disturbance experienced by the psyche (Young, 2000a).

**Conclusion**

To conclude, in this paper I have described how I would work psychodynamically with a client who was experiencing grief and GAD, based on an understanding of Klein’s developmental positions. I provided a description of the positions, their relation to anxiety and mourning and the processes the ego must undergo in order to overcome these states. Additionally, I highlighted how I would draw from Klein’s theory to conceptualise the client’s presenting issues and to identify areas of focus for therapeutic work. An understanding of Klein’s developmental positions can shed light on the unconscious processes which may be activated during stress, thus suggesting therapeutic avenues for recovery.
References


Essay 3: What are the clinical implications of the differences between traditional CBT and ACT when working with clients with chronic pain?

Some argue that whilst there are subtle, albeit important, theoretical and procedural differences between ACT (Acceptance and Commitment Therapy) and traditional CBT (Cognitive Behavioural Therapy), the mechanisms of action are similar to and consistent with CBT approaches and therefore the term “new wave” is misleading (e.g. Hofmann, Sawyer and Fang, 2010). In this essay, I briefly describe traditional CBT and ACT, outlining the differences between them and their relevance to working psychotherapeutically with clients with chronic pain.

CBT

CBT is a family of interventions based on the assumption that there is a causal relationship between maladaptive cognitions and emotional distress and problematic behaviours. CBT posits that irrational or distorted cognitions are key factors in distress and psychopathology. Therefore, CBT interventions focus on modifying the content, intensity and frequency of dysfunctional cognitions, attributions and self-talk by means of cognitive restructuring and behavioural interventions such as exposure, skills training and behavioural activation.

According to Beck’s (1976) cognitive content specificity hypothesis, each psychological disorder is characterised by disorder-specific cognitive content. This hypothesis has guided therapeutic interventions and empirical research which has generated evidence suggesting that treatment efficacy is contingent on tailoring protocols to specific disorders and targeting specific cognitive content. However, recent research has emerged which, although acknowledging the importance of cognition in psychological functioning, challenges traditional cognitive accounts of change which contend that direct cognitive restructuring mediates therapeutic outcomes (Longmore & Worrell, 2007).
ACT

ACT is a model of intervention based on the view that a large proportion of psychopathology stems from cognitive fusion (i.e. literal thinking/experiencing thoughts as reality), individuals’ attempts to control or avoid distressing or uncomfortable psychological experiences and a lack of clarity regarding one’s core values and goals (Hayes, Masuda, Bissett et al., 2004). These processes result in psychological inflexibility and a lack of effective action. Therefore, ACT aims to reduce cognitive fusion and experiential avoidance by developing mindfulness, encouraging psychological acceptance and helping clients to identify and behave in accordance with their core values (Vilardaga, Hayes, & Schelin, 2007).

A fundamental tenet in ACT is that psychological distress is a normal part of human experience. Therefore, instead of trying to change dysfunctional cognitions, ACT focuses on increasing behavioural effectiveness and developing psychological flexibility so that clients can pursue rewarding lives in spite of their unpleasant thoughts, emotions and sensations. Whilst reducing cognitive and emotional distress is not the goal of ACT, it is often a by-product of this process (Harris, 2008). As ACT targets the entire experiential avoidance system rather than specific beliefs (Ciarrochi & Bailey, 2008), ACT is arguably effective trans-diagnostically.

Theoretical underpinnings

ACT and CBT differ significantly in terms of their ontological and epistemological assumptions, which has implications for clinical practice (Hayes, 2004a; Vilardaga et al., 2007). Hayes (2004a) outlines how second-wave CBT interventions typically target cognitive content directly through testing, challenging negative thoughts and developing alternative explanations (Hayes, 2004a). These interventions are based on the mechanistic assumption that the form and frequency of thoughts have a direct emotional and behavioural impact (Hayes, 2004a). However, post-modernist theories and changes in philosophy of science challenged the underlying assumptions of
second wave CBT and helped to shift the focus from the form or frequency of cognitions and first-order change strategies to broader factors, such as the function of thoughts, the context in which psychological events occur and the change strategies associated with specific thoughts (Hayes, 2004a; Vilardaga et al., 2007).

Furthermore, ACT stems from a philosophical approach called functional contextualism (FC) and from Relational Frame Theory (RFT). In CBT, emotions and thoughts are viewed as antecedents of behaviour, whereas in FC they are viewed as behaviours in themselves (Ciarrochi & Bailey, 2008). The ACT therapist therefore treats all psychological events as behaviours and focuses on increasing value-congruent behaviour rather than analysing the accuracy and relationship between thoughts, beliefs and emotions. Furthermore, therapists focus on behaviour in context and think in terms of the cognitive function of the behaviour rather than its form (Ciarrochi & Bailey, 2008). Consequently, thoughts are evaluated in terms of how useful they are in helping clients reach their goals in a particular context, rather than in terms of their accuracy (Harris, 2008). This is particularly relevant when working with clients with long-term conditions such as chronic pain, where distressing thoughts such as ‘my pain will never go away’ do not constitute ‘cognitive distortions’.

RFT is a behavioural theory of human language and cognition which underlies ACT. From an RFT perspective, normal language processes involve “relating stimuli (objects, people, things, thoughts, memories, emotions etc.) in ways that change how we perceive and react to these stimuli” (Dyden, 2011, p. 16). The implications of RFT for therapists are that language processes can dominate over experience (even if our experience is inconsistent with our verbal constructions), language changes experience, language greatly expands targets of avoidance and language processes are controlled by context (Ciarrochi & Bailey, 2008). Therefore, disrupting client’s learned relational responding processes (e.g. through cognitive defusion) can help to reduce the impact of verbal processes on their experience and behaviour. Another key contribution from RFT is that it is not only the form or frequency of cognitions but the
context in which they occur that makes them powerful (Hayes et al., 2004). Therefore, rather than changing the content of thoughts, interventions should focus on changing the context in which they are experienced, thus helping clients to experience them differently.

Additional underlying assumptions

The assumptions underlying each model in terms of the nature of thoughts and emotions also differ. Firstly, while traditional CBT posits that cognitive change “is a necessary or primary method of clinical improvement” (Hayes, 2004a), ACT posits that changing thoughts and feelings is not necessary in order to change overt behaviour. Therefore, ACT uses a range of techniques which have been found to be effective in CBT but focuses on changing overt behaviour or life situations rather than automatic thoughts and feelings, or past-related private events (Hayes et al., 2004).

Additionally, CBT and ACT differ in terms of the process through which therapeutic change is achieved (Hayes, 2004b). CBT aims to help clients think more logically/rationally about their experiences, assuming that this will lead to emotional and behavioural change. Conversely, whilst ACT influences thought change, it does not use logico-rational strategies to do so. ACT focuses on changing the function of psychological events rather than on modifying the events themselves (Hayes, 2004a). Change in functionality is developed through the six core principles of ACT: cognitive defusion (i.e. learning to identify thoughts as thoughts), acceptance, self-as-context, present moment contact, values and committed action. The first four are collectively known as ‘mindfulness skills’ and combined with the latter two are argued to increase psychological flexibility (Harris, 2008). More specifically, ACT encourages clients to mindfully notice and accept their thoughts and feelings and aims to reduce obstacles to effective action (i.e. cognitive fusion and experiential avoidance). Therefore, it uses metaphors to illustrate alternative ways of thinking about experience, values clarification to encourage clients to think of how to live value-driven lives and self-as-context strategies to help clients develop a sense of self that is distinct from their
thoughts and emotions (Dryden, 2011). ACT cases can be conceptualised in terms of how well clients embody each of the six core processes of ACT, which provides therapists with a sense of which of the processes clients will require more help and support with.

The therapeutic objectives of CBT and ACT also differ. CBT aims to reduce the frequency and intensity of distressing thoughts and emotions and the process of change involves feeling better by working towards feeling better. However, in ACT clients are encouraged to renounce feeling better, accept their distress and work towards living in line with their values despite their distress. Feeling better, if it occurs, is a by-product of living a meaningful life rather than a therapeutic objective (Harris, 2008).

**Strategic and technical differences in relation to working with chronic pain**

Given the nature of the experience of chronic pain (i.e. some aspects can be improved and others cannot) an integrated model which supports clients in changing what they can change and accepting what they cannot change can be effective when working with chronic pain. Ciarrochi and Bailey (2008) advocate a Flexibility Model of practice which integrates CBT and ACT processes: while CBT processes would include techniques to alter the form and frequency of thoughts, increase emotional understanding and skills training, ACT processes would include defusion, mindfulness, self-as-context and values techniques.

Contemporary CBT approaches for chronic pain frequently focus on identifying the cognitions that determine pain-related behaviours in order to modify them in the service of helping clients increase control over their lives and engage in more active life-style (Sage, Sowden, Chorlton & Edeleanu, 2008). These include:

“fear of harm or re-injury, perceptions of having low control over the pain, low self-efficacy for managing pain and catastrophic thinking about the future, together
with associated behavioural responses such as avoidance of activity, cycling between under- and then over-activity, and hypervigilance to bodily sensations” (Sage et al., 2008, pp. 30-31).

Pain-related cognitions and behaviours can become risk factors for the development of chronic pain and therefore timely identification and modification of pain-related cognitions and behaviours can improve client outcomes (Sage et al., 2008).

CBT interventions such as graded activities and graded exposure can be effectively used in chronic pain work to increase client activity (Sage et al., 2008). Graded activities encourage clients to gradually increase engagement with specific activities, while graded exposure explicitly targets the fears underlying inactivity by encouraging clients to engage in increasingly fear-provoking situations (Sage et al., 2008). The aim is to reduce the threat of the feared situation and modify cognitions through gaining new evidence. Graded exposure has been found to be more effective than graded activity in decreasing pain-related fear, pain catastrophising and pain vigilance among others (Roelofs et al., 2002).

Behavioural activation also involves increasing clients' engagement with positively reinforcing activities by identifying pleasurable activities to set as goals and designing steps towards those goals. While CBT uses behavioural experiments to challenge dysfunctional beliefs, to help clients to have more positive experiences and to reduce distress, in ACT behavioural activation is a goal in itself. Behaviours are chosen not because they will help clients to have more pleasurable experiences but because they will help clients move towards their values (Dryden, 2011). Therefore, chosen values-consistent behaviours may actually increase distress.

Indeed ACT utilises several CBT techniques in different ways and for different purposes. The aim is to promote cognitive restructuring while avoiding cognitive challenging and to focus on the context and consequences of thinking rather than its content (Ciarrochi & Bailey, 2008). For instance, while exposure is traditionally used
to alter cognitive content by exposing clients to the stimulus until the fear response is unlearned, in ACT exposure aims to help clients practice willingly experiencing and tolerating aversive emotions (Dryden, 2011). In the light of the central role played by fear-avoidance in the development and maintenance of chronic pain and disability, ACT's emphasis on acceptance to counter experiential avoidance can prove useful.

The initial stage of cognitive restructuring in CBT involves cognitive distancing which is similar to defusion. However, from a CBT perspective, the thought must then be changed for a more logical/functional one. In ACT on the other hand, cognitive and affect/sensation change strategies are minimised, as cognitive change is not considered necessary for behavioural change. Similarly, thought diaries can be used in ACT but the emphasis is on external behaviours rather than thoughts or emotions.

Skills training is also used in ACT, although the emphasis tends to be on addressing private events that prevent clients from moving towards goals while practicing willingness, defusion and identifying values (Ciarrochi & Bailey, 2008; Dryden, 2011). Additionally, skills are acquired primarily through experiential exercises rather than verbal instruction, and debriefing after exercises is discouraged to avoid cognitive fusion.

CBT concepts such as vicious cycles, automatic thoughts and hot-cross buns are often used in therapeutic work with chronic conditions (Sage et al, 2008). Additionally, some CBT strategies can be helpful when working with chronic pain including: promoting emotional understanding; creating names and descriptions for cognitive processes (e.g. teaching clients about thinking errors, rumination, "shoulding"); cognitive restructuring (i.e. developing new knowledge through psychoeducation and behavioural experiments); altering the form and frequency of cognitive relations (e.g. challenging thoughts, beliefs and metacognitions and developing self-esteem); environmental change strategies; affect/sensation strategies (e.g. progressive muscle relaxation, attentional training) (Ciarrochi & Bailey, 2008). However, Ciarrochi and Bailey (2008) caution that some of these approaches may "reinforce the notion that
thoughts and feelings are “reasons” for doing something” (p. 60) and that sense-making, problem solving, reasoning or evaluation may place the emphasis on problem solving and ‘fixing’ rather than creating a mindful and accepting space. Therefore, care must be taken to emphasise that thoughts and feelings do not necessarily cause behaviour and to focus on unanalysed experience rather than verbal processes (Ciarrochi & Bailey, 2008).

While CBT can help to identify what can be changed and take steps to achieve it, its effectiveness is limited in cases where circumstances cannot be changed. Hayes et al. (1999) contend that the brain is a problem-solving machine which identifies, assesses and eliminates problems. Though effective in many contexts, this becomes problematic when applied in contexts where a solution is not possible (e.g. chronic conditions), leading to a tug-of-war between the unsolvable problem and our problem-solving brain. Being stuck in this struggle increases suffering. Additionally, Ciarrochi and Bailey (2008) argue that when clients’ views and/or experiences of therapy are mechanistic, they may become attached to the idea that they must ‘fix’ their dysfunctional beliefs or problems in order to achieve valuable changes in their lives. This can lead to ‘stuckness’ in client’s lives and in therapy in which case an ACT approach can be helpful.

The efficacy of ACT has been demonstrated across a range of psychological difficulties including chronic pain conditions (Dahl & Lundgren, 2006). While chronic pain cannot be eliminated, ACT aims to reduce the sufferings the person experiences because of the pain.

ACT distinguishes between pain and suffering. From an ACT perspective, it is the alterations people make to their lives and plans in order to avoid or control their pain that result in increasingly restricted lives and produce suffering (Dahl & Lundgren, 2006). Similarly, from an ACT perspective, experiential avoidance and control strategies produce secondary or ‘dirty’ distress. ‘Clean pain’ is the physical sensation of pain whereas ‘dirty pain’ is the suffering that arises as a result of people’s cognitive
and behavioural avoidance reactions to pain (Hayes, Strosahl & Wilson, 1999). Dirty pain manifests itself as mental scripts, avoidance behaviours and values illness (i.e. experiential avoidance, resulting in a move away from valued-living) (Dahl & Lundgren, 2006). In such cases, ACT can help reduce the suffering generated by people’s efforts to control or avoid experiences. The main therapeutic aim would be to help clients to change the way they relate to their pain in order to modify the effects of pain in their lives.

ACT’s therapeutic strategies involve: highlighting the cost and futility of experiential avoidance; developing acceptance and defusion skills to encourage contact with psychological content and experience and to undermine the literal meaning of thoughts; enhancing present moment experience; developing a sense of self-as-context to reduce the threat of psychological content; clarifying values and distinguishing them from goals and actions; and encouraging value-congruent behaviour (Hayes, 2004b).

Firstly, therapy involves helping clients to let go of control strategies they have been using to try to reduce their pain and to accept the distressing thoughts, feelings and physical sensations associated with their pain. ACT uses a process called creative hopelessness to help clients shift from an experiential control agenda (Dryden, 2011). The aim is to help clients identify which of their coping strategies do not work, so that they may develop alternative ones. The therapist does not confront the client’s coping strategies but uses a range of metaphors and interventions designed to highlight the futility and paradox of experiential control (Dryden, 2011). Acceptance skills are promoted through experiential interventions aimed at helping clients to embrace uncomfortable feelings, thoughts and physical sensations. Defusion is achieved through altering language conventions and objectifying psychological content through the use of metaphors and experiential exercises (e.g. Dryden, 2011; Harris, 2008; Hayes & Smith, 2005). Contact with the present moment is developed through a range of mindfulness exercises.
Therapists using an ACT approach help clients learn to distinguish between their 'clean' and 'dirty' pain by using a pain diary and helping clients to undermine their dirty pain. Clients are encouraged to live with their pain rather than in opposition to it and to make longterm life-shaping choices based on their values rather than their pain. The process of value clarification, graduated goal setting and activity scheduling helps clients to take committed action towards their values and live a more meaningful life.

Therapists help clients to distinguish between outcome goals and underlying values and to focus on valued living rather than goal attainment. Distinguishing between values and goals and exploring new ways in which clients can pursue their values can be helpful when working with people whose way of pursuing values has been compromised by their chronic pain. Therapy focuses on reducing the discrepancy between clients' values and behaviours. The 'values compass' exercise helps clients to identify their values across different life domains and to evaluate to what extent their actions are values-coherent in order to develop concrete behavioural goals to align their actions with their values (Dahl and Lundgren, 2006).

During the goals and action planning process, ACT makes use of CBT tools such as activity scheduling, behavioural homework and exposure. However, the aim is not to reduce distress or increase pleasurable activities but to help clients to engage in potentially distressing, value-driven behaviours using mindfulness, defusion and acceptance skills (Dryden, 2011).

In the final phase, ACT therapists aim to enhance their clients' psychological flexibility and engagement with committed action by helping them to: identify and distinguish between possible internal and external obstacles that may arise while pursuing their values; apply the skills they have learned to manage obstacles; focus on valued living rather than goal attainment; and recommit after setbacks (Ciarrochi & Bailey, 2008; Dahl and Lundgren, 2006).
Conclusion

While some CBT and ACT interventions are similar, their emphasis and assumptions differ. An ACT model may prove valuable in cases where a traditional CBT approach is limited or has become stuck. Combining ACT and CBT techniques when working with clients with chronic pain more effectively addresses clients’ needs by supporting them in changing what they can change and accepting what they cannot change, thus reducing their suffering and helping them to live value-driven lives.
References


This dossier includes a description of each placement, including a description of the context and duration of each placement, the theoretical orientation of each placement, the client groups I worked with and the types of supervision I received. Other professional activities I was involved in are also described. As part of my training, I wrote six in-depth Client Studies/Process Reports illustrating my individual work with different clients whom I worked with across the different clinical placements. Additionally, I developed logbooks for each placement which provide an account of my therapeutic practice and further learning opportunities at each placement. The Client Studies/Process Reports and log books can be found in the Appendix to the Portfolio. However, identifying information about the placements, clients and supervisors has been omitted or altered for confidentiality purposes. The therapeutic practice dossier concludes with my final clinical paper which describes my personal and professional development as a counselling psychologist throughout the course.
First Year Placement

A university counselling service (November 2010 - July 2011).

My first placement was at a University Counselling service which aimed to promote and develop the awareness of emotional, psychological and physical health amongst undergraduate and postgraduate students and staff. The multi-disciplinary team consisted of six counsellors/ psychotherapists with different therapeutic approaches (e.g. humanistic, integrative, mindfulness-based, CBT), three counselling psychology trainees on placement, a mental health advisor and a coordinator. In addition, the service worked in collaboration with the Medical Centre and Student Healthcare. Clients were usually self-referred or referred by the Medical Centre, the mental health advisor, or other student support staff (e.g. student advisors/ tutors). The client population was varied in terms of age, gender, ethnicity, religion and, to an extent, socioeconomic background. The services provided included one-to-one drop-in and crisis sessions, time-limited individual counselling (usually six sessions), ongoing groups and workshops and access to self-help resources. When possible and appropriate, the service offered longer-term individual therapy.

Throughout my placement, I provided individual therapy drawing primarily from the person-centred framework. I had the opportunity to work with a range of clients of different ages, religions and cultural backgrounds. Additionally, I had the opportunity of working with clients with a range of presenting difficulties including anxiety, social anxiety and isolation, depression, bereavement, relationship breakdown, self-identity issues, abusive relationships, obsessional jealousy, academic issues and low self-esteem. My supervisor offered weekly individual supervision and was a registered psychotherapist who used an integrative approach to therapy and supervision, although there was an emphasis on person-centred approaches for training purposes. However, I was well supervised and supported when I thought it would be helpful to draw from other approaches, such as CBT, in my clinical work with specific clients. I found this flexibility constructive and stimulating.
With regard to other placement activities, I also carried out assessments, maintained written records of each session, liaised with Student Healthcare and clients’ personal tutors and wrote end of therapy reports for each client. Additionally, I attended monthly clinical meetings and monthly seminars/presentations which I found very enjoyable and interesting as they addressed a range of therapeutic issues and challenges which we had chosen as a team because of their relevance to our clinical work. Furthermore, I co-presented a seminar with a colleague, addressing sexual issues and how these could be approached with clients and colleagues. I also attended weekly group supervision at the university.

Second Year Placement

A charity providing therapy to child and adolescent victims of domestic violence (September 2011 - August 2012).

My second placement was in a specialist service which formed part of a domestic violence intervention programme that aimed to support vulnerable women and children. The charity where I was based provided psychodynamic and child-centred therapy to child and adolescent victims of domestic violence aged between three and seventeen years old. The service offered semi long-term therapy (up to five months subject to review), although the service was flexible and could offer therapy for up to one year. The centre also offered supervised contact for perpetrators and their families. The multi-disciplinary team consisted of two counselling psychologists, four counselling psychology trainees on placement, two social workers and a coordinator. Additionally, the centre worked closely with a range of other services in order to address the children’s needs holistically. Referrals were accepted from all sources, although clients were usually referred by social services or by their primary caregiver. The lead psychologist would assess the client’s difficulties in an extended assessment with the child and the primary caregiver, which would be shadowed and written up by a trainee, and would assign each client to different trainees. A precondition for therapy was that the children were no longer exposed to domestic violence.
I worked at the centre and at a school where I offered individual child-centred play therapy informed by psychodynamic theory. I also drew from a range of different therapeutic resources and techniques including child therapy books and creative arts with the aim of offering children a safe, consistent and confidential space to be able to work through their difficult feelings and experiences. This placement was emotionally and intellectually challenging and required a lot of additional reading about trauma, attachment and child development as well as making good use of supervision and personal therapy. However, whilst it was a demanding year, it was also very enriching and stimulating. I was able to work with a range of clients of diverse ethnicities and of different ages and developmental stages (my clients ages ranged from 4-13 years old). Clients had experienced and/or witnessed physical abuse, sexual abuse, emotional abuse and/or neglect and their presenting issues included: traumatic symptoms (e.g. nightmares, anxiety, aggressive behaviour), attachment and relationship difficulties, emotional regulation issues, low self-esteem, behavioural issues and health problems. In addition, a number of my clients had experienced trauma very recently and were living in refuges at the start of therapy and therefore they also faced context-specific challenges. Furthermore, a number of the clients’ parents had suspected or confirmed mental health difficulties and substance abuse problems.

In terms of supervision, I was offered weekly individual supervision. However, as a result of changes within the organisation I had three consecutive supervisors throughout the year. Two were counselling psychologists and one was a psychotherapist. Although this felt disruptive and frustrating at times, it was also an invaluable experience in terms of experiencing different supervisory styles within the same placement/therapeutic model. I also attended weekly group supervision at the University and I attended additional peer supervision sessions with other trainees from my placement where we explored challenging cases (e.g. silent or sexualised children or children who don’t play) and shared techniques and resources to help children explore their emotional worlds and to identify and manage therapist burn-out.
Additional placement activities involved: attending a two-day training course organised by the placement, which addressed issues around domestic violence; working with vulnerable populations; trauma; risk; and child protection. In addition, I was interviewed by an Ofsted Inspector at the offsite base. I was also responsible for recording my clinical notes after each session, bearing in mind that these may be communicated to social services and other relevant agencies, and for writing end of therapy reports for each client. Unfortunately, owing to timetable clashes and cancellations, I was not able to shadow any of the assessments. However, I was able to read the written assessments and integrate the information into my formulations. It was also interesting to compare how the primary caregiver spoke about the child and how the child presented in therapy and to incorporate ‘discrepancies’ into the formulation.

Third Year Placement
An NHS Community Health Psychology Service (September 2012 - September 2013).

In my final placement, I worked in secondary care with a specialist NHS team which provided for the psychological needs of adult patients and their carers, whose emotional or mental health problems were either caused by a physical health problem, thought to be making it worse or making it hard to manage. The service mainly worked alongside the primary health care team providing therapy for outpatients. Clients were referred by GPs, consultants or other health professionals and were seen for an average of six, usually fortnightly, 50 minute sessions. The team consisted of seven Clinical and Health Psychologists and a counselling psychology trainee, who provided CBT and ACT. In addition, team members worked in a range of departments across different acute hospitals, where they worked alongside health care professionals (e.g. specialist nurses/therapists and doctors) as part of multidisciplinary teams.
During my placement, I was based both in the specialist department, where I worked once a week for the duration of my placement, and in two different departments at an acute hospital, spending half of my placement in each. I offered short- and mid-term therapy informed by CBT, ACT and Mindfulness to individual clients and tailored to their presenting difficulties. I also co-facilitated a weekly two-hour ACT-based pain management group, with approximately eight attendees, at one of the hospitals. In this placement, I was able to work with a variety of clients with a broad range of long-term health conditions arising from illness or accidents and which included multiple sclerosis, stroke, tetraplegia, paraplegia, chronic fatigue syndrome, PTSD, Meniere's Disease, Tinnitus, Chronic Obstructive Pulmonary Disease, Cancer, Diabetes and chronic pain. My case load age range was between sixteen and seventy-seven and I was able to work with clients of diverse ethnic backgrounds and socioeconomic status. My supervisors were all Clinical Psychologists and I was offered weekly individual supervision by each of the three supervisors at each specialist department, which meant that at times I had supervision twice a week with different supervisors. This was an invaluable experience, especially as the supervisors could provide specialist supervision pertinent to each specialist setting and because, for training purposes, different supervisors focussed on ACT or CBT approaches, which really helped me to understand the different approaches and to conceptualise and formulate therapy from the different perspectives.

This placement offered numerous opportunities in terms of additional activities and training. I attended monthly departmental meetings and regular ACT clinical supervision with my colleagues, as well as regular MDT meetings and departmental strategy meetings at the hospital. Additionally, I was able to take part in an eight week Mindfulness-Based Stress Reduction course and obtain a certificate which will enable me to continue my training to become a certified MBSR practitioner. I also participated in a six week ACT and Physiotherapy-based group for chronic pain. In addition to the organisational and departmental inductions, I completed all the statutory and mandatory training required, which included training on safeguarding adults and children, risk management, basic life support, information governance, how
to use different databases and systems at my different locations and a seminar on changing healthcare environments, among others. In addition to conducting assessments for individual therapy, I co-conducted assessments for the ACT-based groups which my colleague and I planned and co-lead with a physiotherapist.

Furthermore, I was able to shadow numerous individual assessments, across the different settings and including a neuropsychological assessment, and to attend a joint assessment at a CMHRS, where I referred a client who was experiencing severe and complex PTSD. I was also able to shadow patients’ visits at the hospital when they were being assessed by doctors, followed up by nurses or undergoing different procedures. Additionally, I attended a conference about one of the conditions I was working with. I was also required to administer pre- and post-therapy psychometric tests, to record assessments, outcome measures and session notes on RiO, to liaise extensively with other healthcare professionals and to write end of therapy reports for each client and referrals to other services when appropriate. I was also able to engage in educational activities such as presenting my research to the team at one of the hospital departments I worked in, co-leading a psychoeducational meeting with patients from the department and speaking briefly at a couple of lectures about my experience of working with ACT and CBT.
Sarah: Through dangers untold and hardships unnumbered, I have fought my way here, to the castle beyond the Goblin city.

Thus begins the film Labyrinth (Lazer, Lucas & Rattray, 1986), a story about a girl called Sarah whose brother is taken away by the king of the Goblins to the castle beyond the Goblin city which lies at the heart of the labyrinth. She has 13 hours to solve the labyrinth and rescue her brother or he will be turned into a Goblin. In the labyrinth, Sarah faces all sorts of challenges and setbacks in a place that is constantly changing, where nothing is what it seems, nothing can be taken for granted and where choosing the wrong door could lead to certain death. On her journey, she meets many interesting and colourful characters, forges strong and lasting relationship and finds her inner strength.

I watched this film countless times as I was growing up and, in one of my recent trips down memory lane, I was struck by how much it resonated with my experience throughout this course. Metaphors and stories are wonderful things, I think, as they can communicate so much more when language falls short of conveying our experiences. Indeed, trying to describe all that I have learned and how I have developed as a person and a practitioner throughout this course seems impossible, but I will try to provide an honest and open overview of my most significant learning experiences and how they relate to who/how I am and consequently to the type of relationship I can offer my clients. As I have had the chance to give voice to the more academic and research-based aspects of myself in other pieces of work, I would like to use this paper as a space to reflect on my growth and development at a more personal level. To help illustrate my narrative, I will refer to characters and scenes from Labyrinth which represent important aspects of my journey.
Sarah: I have to solve this labyrinth. There aren't any turns or openings. It just goes on and on!
Worm: It's full of openings. Just you ain't seein' them.
Sarah: Where are they?
Worm: There's one right in front of you.
Sarah: No, there isn't. […]
Worm: Of course there is. Try walkin' through it. You'll see what I mean.
Sarah: What?
Worm: Go on, then.
Sarah: That's just wall. There's no way through.
Worm: Things aren't always what they seem in this place, so you can't take anything for granted.

The first year laid the foundations for my practice and my way of ‘being’ therapeutically. It was exciting, challenging and terrifying and I often felt lost and stuck. During first year, I discovered important things about myself which I had previously been unaware of and which had a bearing on my way of being and my practice. The challenge involved incorporating these insights into my personal and professional development. For instance, I gradually realised that I was a ‘doer’, especially when faced with difficulty or anxiety. My natural tendency was to jump into action and try to ‘sort things out’ or ‘make things better’. I also learned that I had a tendency to avoid difficult emotions. This was a difficult realisation for me, especially as a fledgling trainee, as I had never considered myself as someone who shied away from emotions, and it did not bode well for an aspiring counselling psychologist. However, there it was: in my supervision, in my process reports, in the room. Something difficult would emerge and I would jump into action, change the subject, start rambling on or go into psychoeducational mode. For instance, when Miss P² cried, I talked excessively rather than staying with the difficult emotions, believing that it would be best ‘not to open the floodgates’ (See Appendix). Initially, I believed I was rescuing clients from difficult emotions but I slowly realised I was rescuing myself.

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2 Clients have been given pseudonyms and identifying information has been removed.
The first friend Sarah makes is Hoggle, a dwarf sent by the Goblin king to ensure that Sarah doesn’t make it to the Goblin city. His role is to ‘befriend’ Sarah so that he can discourage her and lure her back out of the labyrinth:

Hoggle: What you've got to do is get out of here. I know a short cut out of the labyrinth.
Sarah: No! I'm not giving up now. I've come too far! No, I'm doing ok.
Hoggle: Of course you are. But it gets a lot worse from here on in.

Hoggle is driven by fear of the king and often walks away from experiences out of fear. Learning to recognise and understand my inner Hoggle, the part of me that tries to talk me out of taking risks, that fears suffering and wants to run for the hills as soon as I smell trouble was humbling and invaluable. When Sarah calls Hoggle ‘friend’, he begins to struggle between his fear of the king and wanting to help her, and thus, although his role is initially that of saboteur, he ultimately overcomes his cowardice and plays a crucial role in helping her to defeat the giant robot that guards the gates to the Goblin city. Similarly, once I managed to accept and befriend/integrate the Hoggle in me, which I had disowned because he was incongruent with my ideal self, I became stronger and better able to recognise when my fear and avoidance were taking over. Furthermore, experiencing empathy and unconditional positive regard for different aspects of myself enabled me to then offer these to others.

My difficulty in tolerating uncomfortable emotions also meant that I struggled initially with the person-centred approach because, whilst I understood that Roger’s core conditions constituted the fundamental basis of therapy and were necessary for therapeutic change (Rogers, 1957), I struggled to see them as sufficient. I found it hard to ‘just sit’ with clients’ difficulties. I wanted to ‘fix’ things and felt incompetent because I couldn’t ‘make them better’. I felt as if the person-centred model didn’t ‘go anywhere’ and, like Sarah with the labyrinth, I felt the model offered no turns or openings. I literally felt as though I had hit a wall and there was no way through. This paralleled my personal life too, where I struggled miserably with loneliness and isolation, having left my family and friends behind to come onto the course. It took a
while to build a life here and my loneliness felt like a thick wall around me. Supervision and personal therapy where invaluable in helping me to discover and understand my difficulties and to personally experience just how powerful the core conditions could be. I slowly learned to trust the process and the relationship and realised that indeed it was only by walking through the process in therapy, supervision and practice that I began to see openings and turnings where previously I had only seen walls.

It was also by repeatedly ‘walking through’ difficult emotions and experiences that I became less afraid and avoidant and gradually developed an awareness of when I’m shifting into ‘doing mode’ and why. This helps to inform my practice because, while I occasionally avoid uncomfortable feelings and become overactive in sessions, I feel that I am now more aware of this tendency and therefore better able to become curious about what it is telling me about what is happening in the here-and-now. Most importantly, my understanding of my role as therapist also started shifting from trying to make things better and ‘taking charge’, to providing a non-directive, client-centred safe space, providing the core conditions and being with whatever emerges in order to facilitate the clients’ own process and development. Thus, I became more at ease with trusting that by providing the core conditions, I was doing/being enough. Having said that, I sometimes did feel that it went ‘on and on’ and I personally believe that the depth of insight provided by the psychodynamic model and the focused and action-based aspects of the CBT model provide more momentum for self-discovery and purposeful change.

Year 2 – Reconnecting with my inner child, understanding dynamics and setting Ludo free.

Wiseman: You want to get to the castle? [...] So, young woman, the way forward is sometimes the way back [...] Quite often, young lady, it seems like we’re not getting anywhere, when, in fact [...] we are.
The psychodynamic year was by far the hardest for me, both personally and professionally. It was also the most transformative year and, although for most of it I felt that a dark cloud had descended upon my head, I came out of it with a renewed perspective of myself and others. I also came to personally experience the value of travelling backwards in order to move forwards.

My second year placement was with child and adolescent victims of domestic violence. Clients’ experiences were harrowing and brought up very uncomfortable and distressing thoughts and feelings. My colleagues and I found ourselves falling into an unplanned pattern of weekly ‘peer supervision’ after work to help us process our sessions and the intense countertransference we experienced. This was a very important year in terms of learning to be kinder to myself. Working with traumatised children was very difficult and I often felt as if I was carrying them all around with me. I felt my head was constantly busy and it was a big challenge for me to learn to switch off and to do things that would nourish and replenish me so that I could be grounded and available.

Getting to grips with psychodynamic theory was also very demanding. I sometimes thought I could literally feel my head expanding, trying to make room for all the theories, definitions, obscurely worded papers, self-scrutiny and dynamics and processes. Additionally, while our work was informed by psychodynamic thinking, it was based primarily on child-centred play therapy (West, 1992). It was a challenge learning to be present in the room, managing disclosures and playing along while being mindful of the dynamics in the room and interpreting them in a child-friendly way.

It’s often said that ‘we get the clients we need’, and indeed my clients helped me learn a lot about developing trust, non-verbal processes and how they can inform our understanding of clients’ inner worlds. The first two children I worked with were severely traumatised and would not speak to me initially (see Appendix). One of them did not talk to me or acknowledge my presence for six weeks. It was tough and I felt
incompetent, but it made me focus on the unspoken/invisible aspects of our process and relationship, and I learned that although sometimes it seemed to me that we ‘weren’t getting anywhere’, in fact we were and I had to learn to be patient and look deeper at the underlying dynamics. Supervision was extremely useful in helping me to hone my ability to see and understand dynamics in the room, recognise the children’s needs and to create a ‘holding environment’ (Winnicott, 1965). My supervisors helped me to look beyond words and to be more in touch with my own internal processes, countertransference and projective identifications, which really helped to inform my practice, especially as much of the work with children was not spoken but expressed through play, body language and movement around the room.

Working with children and studying the literature inevitably made me revisit my own childhood and formative experiences. I reconnected with my inner child and I managed to understand at a much more profound level the importance of attachment, object relations and early developmental experiences. I found myself reassessing every relationship I had ever experienced in the light of this new understanding. This process was messy, chaotic and very destabilising as it brought up a lot of previously unrecognised or unresolved issues. Moreover, I began scrutinising patterns and dynamics in my relationships and realised that I needed to end my relationship with my partner. Although this was difficult, I feel it reflected and facilitated the growth and healing I was experiencing. Therapy was crucial for me throughout the year and my therapist provided a safe and containing space for me to journey back and share and process memories and emotions that often overwhelmed me. My dreams also became a significant part of therapy. It was as if I spent a year shuttling between my self at various stages of childhood/adolescence and my present self, trying to integrate the various parts of myself. I began looking at people differently, being aware of the inner child inside everyone and of the effects of trauma and attachment on development and relationship dynamics. I have not been able to find who expressed the idea that in ‘every person there is a one-year-old, a two-year-old... a seven-year-old etc.’, but I often find myself reflecting on it and being mindful of the range of ages and developmental stages (with their needs, wants, challenges and fears), that exist
inside myself and the person in front me and I hope that this will enable me to access my clients' inner child and help them to integrate it into their whole person. I feel that through my experiences in second year, I connected the dots and gained a clear sense of who I am and how I relate and this new insight has been crucial in helping me to know myself and thereby to be more aware and purposeful in my use of self and in my relationships. I was also reminded of how challenging change, personal growth and therapy can be and to be mindful of this with my clients.

Another defining lesson I learned in second year was the importance of play and creativity throughout the lifespan. The second friend Sarah meets in the Labyrinth is Ludo, a big scary-looking beast whom she finds tied up by Goblins and whom she sets free and befriends. Ludo, whose name originates from Latin and means "I play" (Oxford Dictionaries, 2013), is a gentle and playful creature who remains with her on the rest of her journey and plays a key role in helping her to defeat the Goblin army. On placement, I quickly learned to wear only dark colours because I spent most sessions on the floor playing and painting and not once did I return from placement without sand and paint on my clothes, on my face and in my hair. 'Freeing Ludo' was one of the best things that happened in second year, and I am now a firm believer in the therapeutic and life-enhancing potential of non-competitive play and creative expression. Fun and play are great allies in defeating the Goblins we must face on our way.

Final year - Being with 'what is', compassion, reconnecting with the body and being 'good enough'.

At present I am working with people with long-term/chronic health conditions, which has also been a deeply transformative experience, but in different ways. Crucial issues (some of which I was also able to explore through my research), which I had never fully considered, or which at least were not central aspects of my clinical work, became part of my day-to-day living, working and thinking: health and wellbeing; life and death; embodiment and 'being' in bodies that become ill, stop functioning or are
in constant pain; what to focus on when one has limited time, energy and resources?.... And becoming aware that these issues are actually ordinary human experiences and ultimately pertain to everybody, though most of us most of the time don't like to think about them.

It was a privilege to have the opportunity to work with people who suddenly found themselves trying to make sense of their existence and embodiment, having to make big decisions and finding ways of creating experiences that would add value and meaning to their lives within their circumstances. I learned a lot about courage, resilience, vulnerability and not taking things for granted and I feel that facing my own vulnerability and powerlessness was a very grounding experience and helped me to reorganise my priorities and reconnect with what truly matters to me.

While I had a theoretical understanding of existential issues and embodiment, they had not been as salient in my previous work and I lacked an experiential sense of their importance. Working with my clients, issues of life/death and body/mind and what they represent to each individual were brought to the forefront. I was particularly challenged working with Mr. S, a tetraplegic client who experienced panic attacks. It was difficult to explore his unique experience of panic and to adapt Mindfulness and relaxation exercises, bearing in mind that he could not feel anything from the neck down.

Additionally, while theoretically I was not dualistic, I realised that in practice I had focused primarily on the mind and neglected the body. This placement helped me to realise and address this split. Furthermore, I became aware of my own embodied experience and the mind-body relationship. It wasn't until this year that I realised how disconnected I had been from my body and that this was indicative of more pervasive relationship dynamics. This insight has helped me to pay attention to clients' relationships with their bodies and what they tell us about attachment and object relations (Orbach, 2004) and to ensure that I think of clients holistically.
I was surprised to find myself really struggling to adapt to the directive and short-term elements of CBT, especially as I had really been looking forward to it, because I had had CBT in the past and found it very helpful. I also struggled initially not to lose focus of the relationship by getting caught up in agendas, diaries and hot-cross buns. It took me a while to shift out of the psychodynamic mode, to adapt to the new model and start believing in it again. I valued being able to work collaboratively, as it fits more closely with my natural way of relating. Additionally, while by this stage I had learned the importance of ‘being’, I particularly valued the behavioural element of CBT and found it was empowering for both clients and myself to introduce some ‘doing’ into the equation in order to bring about helpful changes. Especially when the time available was limited. I found CBT very helpful in facilitating positive changes in the lives of certain clients. For example, using graded exposure and relaxation training to help Miss J manage her anxiety so that she could become more independent (see Appendix). However, it was learning ACT which I found most interesting and helpful in my work with most clients.

Approaching therapy with people with long-term conditions from an ACT perspective (e.g. Hayes 2004) has been very enriching and helped to curb my tendency and desire to want to fix things. ‘Acceptance’ was a new concept to me and triggered a radical shift in my thinking as I explored it through my research, practice and studies. Reading The Happiness Trap by Russ Harris (2007) was pivotal in helping to shift my perspective from viewing happiness and wellbeing as the ‘norm’, or as states that can be achieved and dwelled in, to realising that suffering and distress are ‘normal’ and inevitable. It felt like I had had ‘an awakening’ that helped me stop constantly striving to be happy and struggling against difficult experiences and then pathologising myself for not succeeding. For a person who has struggled with anxiety and depression, this was a very important lesson. Making room for my full range of emotions and experiences and noticing them rather than trying to push them down/out has had a huge effect on my energy levels and my mental resources. I feel more peaceful now that I’m not constantly trying to change things and I can really appreciate when things are ok or I feel happy, without becoming upset when I’m not. This new perspective
and compassion for myself and 'what is' lifted a massive weight off my shoulders and paradoxically left me feeling more content. Whether working individually or running ACT-based groups for chronic pain, I found that shifting the focus towards valued living and developing the ability to be with what is, regardless of one's circumstances, also helped to infuse therapy with purpose and agency. Co-creating this shift required that I develop my own psychological flexibility and shifted my focus towards where there is room for manoeuvre and this has been one of my most important milestones.

At the start of the year, I was able to take part in an eight week mindfulness-based stress reduction course (MBSR) (Kabat-Zinn, 2011) which helped me enormously to stop functioning on 'automatic pilot' and become more present and intentional. I became more in touch with myself than ever before and developed my capacity to observe internal changes and to be curious about what they are communicating. As I already mentioned, I used to struggle with distress, but I am now much more confident in my ability to manage my own and others' distress and I feel that mindful awareness has made me a more perceptive person and practitioner. I am now a firm believer in the therapeutic benefits of Mindfulness.

Lastly, therapy, mindfulness and supervision have helped me to identify and curb my perfectionist tendency and to be more compassionate with myself. Another key milestone has been to become comfortable with being 'good enough' and recognising my strengths and qualities. Feeling more comfortable with myself and less driven by perfectionism allowed me to work more freely and creatively and to be less guarded and cautious, taking 'risks' which actually proved beneficial to therapy and to my personal and professional development.

The next friend that Sarah makes on her journey is Sir Didymus, a courageous knight who is willing to face any force or enemy in order to fight for what's 'right'. He fearlessly charges into danger and challenges his enemies with ferocity and bravery, blissfully unaware that he is a small fox-terrier. In many ways Sir Didymus is the opposite of me. The word 'avoidance' does not figure in his vocabulary, and in
situations where I would be running for shelter or struggling with my urge to avoid, Sir Didymus would be charging right in to the cry of “I can climb this mountain!”. While I don’t imagine myself ever being completely like Sir Didymus, and I’m not convinced that it would be a good idea, I do feel that this bolder and more confident part of myself has gradually developed throughout the course. I am aware that I am still a “small” practitioner and have a long road ahead of me. However, I am pleased that my confidence in who I am as a person and as a practitioner, and my ability to face and sit with a range of emotions, difficulties and clients has progressively developed.

Evidence and Theory: ‘What door?’

Sarah: Do you know where the door to the labyrinth is?  
Hoggle: Maybe.  
Sarah: Well, where is it?  
[...]  
Hoggle: Where is what?  
Sarah: The door!  
Hoggle: What door?  
Sarah: It’s hopeless.  
Hoggle: Not if you ask the right questions.

Each client brought different histories, objectives and needs which guided my reading, which in turn helped me to manage my anxiety and sense of inadequacy by providing guidance and a framework with which I could inform my work when I felt out of my depth, stuck, or faced with a new challenge (i.e. constantly!). However, I have also been confronted by the limitations/misuses of ‘evidence’ and theory especially if they take precedence over the relationship and process. To be clear, I believe that theory and evidence are essential and usually very helpful. However, they can also become constraining and distancing and can hinder practice if applied uncritically to complex life situations. For instance, during my CBT placement, I found learning protocols and techniques and working through agendas and homework consumed a lot of time, which often already felt insufficient, and I had to be mindful not to alienate or lose sight of the clients or the relationship and to remain curious. Strawbridge and Woolfe
(2010) remind us that “psychotherapy is, in its very nature, research” (p. 14) and therefore, we must not lose sight of therapy as a medium for inquiry and the sustained exploration and description of human relatedness.

I believe that the main vehicle for change is the therapeutic relationship and the meanings that are created in therapy with my clients. Therapeutic sessions and relationships are co-constructed and unique. Therefore, while a knowledge of theory and evidence is essential, it must not preclude or override an idiographic and phenomenological exploration and understanding of the client’s difficulties in order for the therapy and interventions to be meaningful. Furthermore, theory must be used in a flexible manner, which accounts for unique differences and suits each client’s needs. Corrie (2010) argues that “it is only through experience that we learn how to combine theoretical constructs, models and techniques in ways that are unique to each individual client” (p. 52). I feel that now that I have a broader sense of different models, theories and interventions, the next area of growth for me will be developing and refining the expertise to ‘ask the right questions’ so that I can tailor them to clients’ unique needs.

**The importance of context**

Working across a range of settings (i.e. a university counselling service, a charity and the NHS, both in a specialist service and in two different departments in an acute hospital) helped me to realise the dynamics and influences that arise in different contexts and working within different systems.

Many of the clients I worked with in first year were dealing with adjustment and life transition issues such as leaving home, relationship breakdowns, performance-related stress or bereavements. While I did not view their difficulties as pathological, it was easier to inadvertently conceptualise their issues as intrapsychic phenomena. However, my second and third year placements really brought to life the importance of context, relationships and systems to individual wellbeing. Every child I saw was in
distress as a result of the family system they had been born into. The fact that relationships and family and social systems shape us, for better and for worse, was very salient. Similarly, working in health, which is dominated by the medical model, and where people's wellbeing and opportunities are inextricably tied to their relationship to healthcare and others, I came to realise the complex dynamics of the sociopolitical and medical contexts and their bearing on myself, my clients and my clients' families and carers. For instance, I have had to try to understand the helpful and unhelpful relationships to healthcare that my clients were involved in and how these shaped their sense of agency, responsibility and expectations. Additionally, I have had to be mindful of bureaucratic structures and acknowledging clients' frustration at having to wait six weeks to be seen (especially when they turned out to have been mis-referred and had to wait another six weeks to be seen at the appropriate service), or of helping clients to transition from child and adolescent services to adult services with older people (e.g. deciding whether or not to include a 16 year old in a pain management group with people in their 60's).

Furthermore, although naturally the demands, responsibilities and expectations of my role increased as I progressed through my placements and I gained experience and competence, these were also determined by the contexts I worked in. For example, maintaining the therapeutic relationship and a sense of a safe space with the children, whilst regularly having to break confidentiality when safeguarding issues arose, required a lot of thoughtful management. Additionally, my current placement requires extensive liaising with other healthcare professionals in order to devise and coordinate care plans and manage risk and safeguarding issues. Furthermore, the volume of 'paperwork' and care coordination required for each client often exceeds the amount of time spent in sessions. This was a big change from previous placements and I felt it impinged on my reflective space, so I had to work around it in order to avoid it undermining my practice.

Likewise, I was also able to compare how I function in different work environments. While in my first year I felt quite disconnected, I found the support provided by my
relationships with colleagues and supervisors in subsequent placements invaluable. Similarly, I was able to experience the contrast between the quiet, containing environment in the specialist service department as compared to the chaotic and bustling environment of the hospital and how this impacted on me. I feel these context-related differences reverberated in my client relationships, highlighting the importance of adequate support and supervision for practitioners and how the therapist's own context impacts upon the therapeutic relationship.

After the Labyrinth: ‘Should you need us...’

Didymus: And remember, fair maiden, should you need us...
Hoggle: Yes. Should you need us, for any reason at all...
[...]
Sarah: I don't know why, but every now and again in my life, for no reason at all, I need you-- all of you.

The friendships made and the lessons learned in the Labyrinth live on, as do the relationships, discoveries, lessons and developments that arose from my experience on this course. Being on very different placements has given me the opportunity to work with a range of people at different developmental stages, from childhood to old age, and to learn about important human experiences like relationships, transitions, trauma, abuse, illness, embodiment, compassion and context, among others. I have also been able to experience the strengths and weaknesses of the different theoretical models and the importance to meaningful and ethical practice of understanding each client's subjective experience and world view. Furthermore, my experience has consolidated my belief in the therapeutic relationship as the primary medium for change and highlighted the importance of understanding the processes and dynamics that occur in each unique relationship, as well as the broader contexts which they are embedded in.

Moreover, I have been able to explore my own strengths and weaknesses and what I can bring to relationships through empathy, compassion, acceptance, play, being ‘good enough’, mindfulness and a willingness to be with what is and dare I say, face a few Goblins and uncomfortable experiences and emotions along the way. All these
lessons, and many more, have been invaluable and I am certain that I will draw from and revisit them all as I continue to develop as a person and a practitioner.
References


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Introduction to the Research Dossier

The research dossier consists of a literature review and two qualitative research studies. The literature review, entitled 'Uses of hope in counselling and psychotherapeutic practice: A critical review' explores the existing literature regarding different conceptualisations of 'hope' and their implications for therapeutic practice. The first research report, entitled 'Living with chronic illness: A Grounded Theory study of adapting to chronic illness when diagnosed when young', explores the experiences of people who had been diagnosed with a long-term illness when they were young. Finally, the second research report entitled "Closing the gap': Personal meanings among psychotherapists working with clients with long-term health conditions', uses an Interpretative Phenomenological Analysis (IPA) approach to explore accounts of chronic illness from therapists' perspectives focussing on how practitioners made sense of clients' long-term conditions. Each research paper includes my personal reflections and an appendix including, transcripts, journal formatting guidelines and information sheets provided to participants.
Literature Review:

Uses of hope in counselling and psychotherapeutic practice: A critical review.

Abstract

The present review aims to examine and critique the available literature regarding counselling and psychotherapeutic uses of hope. The review begins with a conceptualisation of hope and is followed by a discussion of the different perspectives on hope, including hope as an emotional, cognitive, behavioural, relational, and developmental or temporal phenomenon. Subsequently, different models and conceptualisations of hope are presented, followed by different perspectives on working with hope therapeutically. Additionally, the issues surrounding hopelessness and ‘maladaptive’ hope and their relevance to therapy are explored. Although substantial research and theory from different psychotherapeutic approaches advocate the therapeutic value of hope, there is little research linking hope theory and practice. Implications for counselling and psychotherapeutic psychology research and practice are discussed and possible areas for further research are identified. The terms counselling and psychotherapy are used interchangeably throughout the paper.

**Keywords:** hope, counselling, therapy, psychotherapy, interventions, hopelessness, hope-focused.
Introduction

In 1959, Menninger addressed the American Psychiatric Association, stressing doctors’ responsibility to foster hope in their clients (Elliott, 2005). Since then, hope has grown as an object of clinical interest and there are now over three decades of research regarding the importance of hope towards physical health and wellbeing (Elliott, 2005). Most extant research and literature on hope comes from the fields of medicine and nursing, and for many years, hope has been dominated by biological discourses (Elliott, 2005). However, more recently hope has also been associated with non-medical positive outcomes such as better academic and athletic achievement, and psychological wellbeing (Cheavens, Scott, & Snyder, 2005). Indeed, the therapeutic value of hope has been increasingly recognised and hope is now considered essential to therapeutic progress (Cooper, 2008). Higher hope is associated with adaptive coping, subjective wellbeing, level of functioning, fewer psychiatric symptoms and confidence that therapy will be effective (Irving et al., 2004). In addition, lack of hope or hopelessness, has been found to be a better predictor of suicidal intent and behaviour than depression (Dyer & Kreitman, 1984). Hope has also been identified as an independent predictor of therapeutic attrition, independently of other measures such as dispositional optimism, expectations and depression with which it is associated (Geraghty, Wood, & Hyland, 2010). Further, hope has been identified as one of the four common factors (the others being the therapeutic relationship, client variables, and therapeutic approach) believed to contribute towards therapeutic change across psychotherapeutic approaches (Hubble, Duncan, & Miller, 1999). However, critics of the common factors approach argue that in order for these factors to be researchable and understandable they must be “conceptually clear, operationally defined, or contextualized within a clinical process” (Sexton, Ridley, & Kleiner, 2004, p. 137). Although substantial research and theory from different psychotherapeutic approaches advocate the therapeutic value of hope, it is not a conceptually clear factor. There is little research linking hope theory and practice and intervention evidence is scarce. Therefore, the aim of this review is to examine and critique the available
literature regarding the therapeutic uses of hope in practice, including different conceptualisations and models of hope and existing intervention research.

The search for research and literature related to hope and practice was conducted using two major electronic databases (PsychINFO and PSYCArticles), containing literature in Psychology and related subjects. The scope of the search included all articles containing the keywords hope and psychotherapy, therapy, counseling, or counselling in the title. In addition, the search was limited to peer reviewed articles published in English between 1972 and 2011. Cited work, including journal articles, chapters and books was also consulted. It should be noted that only the literature relevant to the aims of this paper was reviewed, and that the search was limited to two databases owing to time constraints. Thus, this comprises a selective rather than a systematic review of the literature.

The review will begin with a description of hope, which includes common elements attributed to hope across the literature, and will be followed by a discussion of the different perspectives on hope, including hope as an emotional, cognitive, behavioural, relational, and developmental or temporal phenomenon. Subsequently, different models and conceptualisations of hope will be presented, followed by different perspectives on working with hope therapeutically, and the relevance of hopelessness and ‘maladaptive’ hope to therapy. Finally, implications for counselling and psychotherapeutic psychology research and practice are discussed and areas for future research are identified.

What is hope?

The concept of hope has evolved over time and hope is now regarded in multiple ways. As Eliott (2005) puts it: “Hope is, or can be, positive, negative, divine, secular, interpersonal, individual, social, ideological, inherent, acquired, objective, subjective, a practice, a possession, an emotion, a cognition, true, false, enduring, transitory, measured, defined, inspired, learnt...and the list goes on” (p. 38).
With regard to hope as defined within psychological literature, common elements found in most definitions of hope describe hope as a process of anticipation that focuses on uncertain future outcomes and is personally meaningful (Bruininks & Malle, 2005; Stephenson, 1991). Another common element is the connection between hope and goals, which is what makes hope especially relevant to therapy, where therapeutic goals focus on progressing towards or attaining “desired objects, circumstances, or ways of being” (Larsen & Stege, 2010b, p. 299). However, authors’ definitions of hope differ in terms of whether, and to what extent, they view hope as an emotional, cognitive, behavioural, relational, and developmental or temporal phenomenon. These different perspectives will be examined below.

Different perspectives on hope

Hope as emotion

According to Averill and Sundararajan (2005), what distinguishes hope from similar concepts such as expectancy and optimism is the degree of rationality and emotionality involved in the process. For instance, expectations are based on probabilities (i.e. rational considerations) and show a linear relationship, where higher probability begets higher expectation, whereas hope is emotional and shows a curvilinear relationship to probability, where too low or too high a probability does not justify feeling hopeful (Averill & Sundararajan, 2005). Optimism, on the other hand, combines both rational and emotional elements (Averill & Sundararajan, 2005). It is rational in the sense that the higher the probability the higher the expectation, but emotional in the sense that optimism is also dispositional and thus can be present regardless of actual circumstances (Averill & Sundararajan, 2005).

Additionally, Averill and Sundararajan (2005) conceptualise hope as a creative emotional response. In their view, under certain circumstances, reason and thinking are not enough to help a person manage a situation, and therefore: “where reason fails, and yet action is necessary, we must construct a different story. We call that story “hope”- an emotion that prompts us to action when reason cannot do so” (Averill &
Sundararajan, 2005, p. 146). They view hope as a narrative, a story people tell
themselves and others, which has rhetorical power. This perspective is relevant to the
therapeutic process where clients’ circumstances, resources or motivation may be, or
appear to be, deficient and yet some form of action is necessary in order to produce
therapeutic change. Importantly, Averill and Sundararajan (2005) emphasise that the
meaning derived from emotions is culturally determined, and therefore hope-focused
interventions must be culturally adjusted and relevant.

**Hope as cognition**

While some conceptualise hope as an emotion that drives people towards their goals
(Averill, Catlin, & Chon, 1990), others conceptualise hope as a cognition or
expectation of outcome that drives one’s goal-oriented actions (e.g. Snyder et al.
1991). In hope theory (Snyder et al., 1991), hope is goal oriented, and is
conceptualised as a cognitive process involving three components which reciprocally
influence each other: the ability to set clear goals, develop strategies to achieve goals
and build and maintain the motivation to do so. Snyder et al. (1991) refer to the
perceived capacity to generate goal-oriented strategies as *pathways thinking*, and the
belief in one’s ability to pursue such strategies as *agency thinking*. Agency and
pathways thinking are iterative and additive throughout the process of goal pursuit,
and therefore both must be present for hope to exist (Cheavens, Feldman, Woodward,
& Snyder, 2006). Initially, this model of hope was primarily cognitive. However,
emotions were subsequently added to the model as reactions to achieving or failing to
achieve a goal (Snyder, Cheavens, & Michael, 2005). In other words, instead of
viewing emotions as the origin of goal pursuit, hope theory posits that emotions are
the consequence or sequelae of hope-related cognitions regarding goal attainment
(Snyder et al., 2000). For instance, negative emotions would indicate blocked or
frustrated goals (Snyder, Michael & Cheavens, 1999). Snyder et al. (2005) argue that
the emotions that arise from goal-directed activity then feed back, shaping and
informing subsequent goal-directed thinking. That is, success or failure at achieving a
goal would result in positive or negative emotions respectively, which would in turn
lead to positive or negative thoughts regarding goals, pathways and agency. Therefore,
hope theory posits that goal-related “cognitions drive emotions” and that “those emotions in turn should shape and inform the thoughts of the person” (Snyder et al. 2005, p.112). However, Snyder et al. (2005) emphasise that in their view emotions are reactive, while they believe hope to be active and proactive and thus more aligned with cognitive than emotional processes.

Snyder et al., (1999) argue that regardless of the therapeutic approach, it is through finding a new goal, pathway, or sense of agency that people become hopeful and that any therapeutic approach can be effective to the extent that it helps clients learn new pathways and fosters their motivation to use them. Furthermore, it is argued that cognitive-behavioural psychotherapy is particularly suitable for creating hope because of its focus on “goal setting, strategy generation, and modification of negativistic beliefs regarding goal attainment” (Snyder et al., 2000, p. 659).

**Hope as a behaviour**

Whether it arises from an emotional or a cognitive process, most conceptualisations of hope involve some form of action or approach behaviour towards a desired objective or outcome. Larsen and Stege (2010b) argue that therapists can help clients identify and choose more hopeful behaviours that are conducive to achieving a desired outcome, independently of whether the path towards a goal is still unclear and the realisation of the outcome is not guaranteed and independently of the clients’ actual level of hope. For instance, a client may have no guarantee that a specific course of action will yield the desired outcome, but may engage in hopeful behaviour by taking action in the direction of the desired goal. In this sense, hope-interventions can be targeted at a behavioural level and it is the outcome of the behaviour and the process of trying and learning that help to instil and reinforce hope.

**Hope as relational or inter-personal**

While hope can be viewed as a personal attribute, hope is also derived interpersonally (Eliott, 2005). Hope may be strengthened or destroyed by others, or may be a response to circumstances determined by others (Eliott, 2005). Flaskas (2007) emphasises that
hope occurs within relational and social contexts and provides examples from family therapy, highlighting that families present different patterns of hope and hopelessness, with different family members experiencing and expressing hope differently at different times, and influencing each others' experiences of hope (e.g. being hopeful for the family member who has lost hope), or becoming stuck/ inflexible in hopeful or hopeless roles.

Similarly, in a qualitative interpretive study with HIV peer-counsellors and peer-counselling recipients, it was found that peer counselling facilitates hope, primarily through the establishment of a meaningful connection with another and through the provision of information and changes in perception (Harris & Larsen, 2007). Thus, these findings highlight the relational importance of hope in therapy. Some of the facets that were identified as facilitating hope were argued to be exclusive to peer counselling, in the sense that peers offer a depth of empathy and understanding and credibility derived from a shared experience, which 'normal' counsellors lack in that context. However, many of the facets that were found to facilitate hope apply to non-peer counselling as well (e.g. acceptance, listening, validation, meaning and purpose, goals).

In a modified grounded theory study on bereavement counselling, both therapists and clients viewed hope as conveyed by the counsellor via the therapeutic relationship (Cutcliffe, 2004). More specifically, Rogers' core conditions (unconditional positive regard, empathy and congruence) were found to facilitate the development of the therapeutic relationship, which in turn was considered central in creating hope (Cutcliffe, 2004; Harris & Larsen, 2007). A variation of this perspective stems from the co-constructionist perspective which views hope as co-created by the therapist and client in the therapeutic relationship (Larsen, Edey, & Lemay, 2007). Indeed the importance of the therapeutic relationship to therapeutic outcomes has been extensively documented (Cooper, 2008) and the importance of connection between the client-therapist relationship and hope is present throughout the literature and
across therapeutic approaches (e.g. Cutcliffe, 2004; Hanna, 2002; Cheavens et al., 2006; Larsen & Stege, 2010a, 2010b).

**Hope as developmental and temporal**

Bergin and Walsh (2005) highlight that hope has a present, past and future and emphasise the value of a developmental perspective on hope, which places hope within the context of each client’s lived experience of hope. Indeed, although hope is regarded as essential to life and as an element that is usually present, with loss or lack of hope being associated with negative consequences (Eliott & Olver, 2009), hope changes, fluctuates and develops over time, in terms of the object of hope, life stages, and internal or external circumstances e.g. ageing, illness, bereavement, or over the course of therapy (Cutcliffe, 2004; Edey & Jevne, 2003; Eliott & Olver, 2009).

From an Eriksonian (1964) perspective, hope begins to develop in infancy by means of adequate infant-caregiver interactions and responsive parenting, which enable the infant to acquire the ability to balance mistrust and trust. Erikson argued that hope is linked with survival, socially reinforced and continues to develop across the lifespan. Similarly, Snyder’s (1994) hope theory posits that hopeful thinking begins to be acquired in infancy as a result of the quality of the caregiving relationship and that individuals’ learning histories will reinforce high-hope or low-hope thinking, thus determining individuals’ dispositional hope.

Bergin and Walsh (2005) highlight that in psychotherapy with clients with chronic or terminal illness or older adults, the time-hope relationship is different to that of other clients and this impacts on where they can invest their hopes for therapeutic change. In addition, older adults and ill people face specific problems, such as dependence and physical and cognitive decline, with their concomitant losses and psychological struggles, which also impact on what they can hope for and how often their hopes must be readjusted in line with their changing circumstances. Bergin and Walsh (2005) emphasise that by adopting a lifespan view of the clients’ experiences of hope, rather than a dichotomous hopeful/hopeless view, therapists can assess the ego
strength and vulnerability of clients, and ascertain whether their therapeutic work with individual clients should focus on fostering and maintaining ‘realistic hope’, the work of despair (i.e. relinquishing hopes and attaining a more integrated sense of self), or surviving rather than thriving, by supporting and strengthening existing coping resources.

A lifespan and dynamic perspective on hope has implications for therapeutic practice. Acknowledging that hope changes over time and has a past, present and future can help to explore the client’s hope history and identify opportunities for therapeutic change. For instance, hope is normally orientated towards future goals but can also be used to identify past experiences where hopes were realised, thus providing personal evidence to encourage hope for the present and future (Larsen & Stege, 2010b). In addition, therapy can centre on the concept of ‘possible selves’, which represent future-oriented representations of what a client is hoping to become or hoping to avoid becoming (Berck, 2010).

**Different models and conceptualisations of hope**

**Hope as multi-dimensional**

While Snyder’s (1991) hope theory offers a narrow unidimensional definition of hope, focusing on goal attainment, hope has also been described as a multidimensional process (Dufault & Martocchio, 1985). For instance, a study of hope-interventions in a general psychotherapy setting identified five key dimensions of hope: cognitive, behavioural, temporal, embodied/emotional and relational (Larsen & Stege, 2010b). From a multidimensional perspective, different dimensions of hope can be drawn from to promote or maintain hope in the other dimensions. For instance, past experiences of hope may be drawn from to inspire hope in the present, or the relational dimension may be used to help build hope in the cognitive dimension e.g. identifying who helps to encourage hope in the client when the client does not think there is a reason to be hopeful (Larsen & Stege, 2010b). Moreover, Farkas (2007) highlights that the different dimensions of hope and hopelessness may be experienced independently of
each other. For instance, one may engage in hopeful behaviour while feeling hopeless. Being aware of the multiple dimensions of hope, and that hope may be experienced differently across dimensions, broadens the scope for intervention opportunities and provides the therapist with more potential therapeutic openings.

The “lost hope-ambivalent hope-hope” continuum
In a grounded theory study on couples therapists’ views of hope (Ward & Wampler, 2010), therapists described hope as existing on a continuum of lost hope, ambivalent or low hope and solid hope. They also identified four main overlapping properties that contribute towards one’s level of hope and where one lies on the continuum, which they argue can aid the therapist to identify the status of their clients’ hope and inform therapeutic practice. These properties are action, evidence, options and connection. Individuals who believe there is no evidence that things can improve, that they have run out of options and lost their connection and whose actions are not focused on relationship-related goals, would be located in the ‘lost hope’ category. While individuals who believe there is some “evidence that the relationship can improve, feel they have options and are willing to act” (Ward & Wampler, 2010, p. 223) on them and have some connection, would be located in the ‘solid hope category’. In addition, Ward and Wampler (2010) identify three key processes that help move couples up the continuum of hope. Firstly, creating a hopeful context, secondly increasing hope by stopping negative interactions that drive couples further down the continuum and finally, promoting successful interactions around recurring issues. Thus, this model provides a framework from which to gauge the level of hope in clients and to determine the type of intervention required to promote hope. However, its effectiveness and its usefulness with other client groups has yet to be determined.

The “feeling unable-feeling able” continuum
Rather than viewing hope as lying on a continuum with low or lost hope, Omer and Rosenbaum (1997) describe hope as lying on a continuum with will or desire. According to them, when we feel most able and powerful, we speak of desire, whereas we speak of hope when we feel unable or powerless: “Hope makes us close our eyes,
as in prayer; will and desire make us act" (Omer & Rosenbaum, 1997, p. 227). The
distinction between feeling unable and thinking that one is unable is unclear in their
conceptualisation. However, in this case it is the person’s perceived or actual inability
to achieve a goal that elicits hope. Therefore, in contrast with Snyder’s (1994) hope
theory where hope arises from pathways and agency thinking, it is the absence of
agency (the belief in one’s ability to pursue goal-directed strategies) that elicits hope.
In addition, while Omer and Rosenbaum (1997) describe hope as arising from
powerlessness and resulting in inaction, Averill and Sundararajan (2005) describe
hope as the emotion that drives one to action when reason fails.

**Hope as narrative and social construction**

Hope has also been conceptualised as a narrative that shapes individuals’ experiences
and perceptions (e.g. Averill and Sundararajan, 2005; Hanna, 2002; Jenmorri, 2006).
Averill and Sundararajan (2005) describe hope as a narrative with rhetorical force
involving a desired but uncertain future. They describe three types of hope narratives:
wish-based, coping-based, and faith-based. While wished-based hope narratives
involve a degree of idealism in wishing for an uncertain outcome, coping-based hope
narratives are more pragmatic and involve situational assessments to determine the
required action (Averill & Sundararajan, 2005). They argue that wish-based and
coping-based hope are synthesised by faith, which thus constitutes a more complex,
albeit unstable form of hope (the authors use the term faith not to refer to any
particular creed, but to the cognitive structure or belief system that makes desired
outcomes seem possible even when unsupported by fact or reason). Although they
argue that hope is a primarily emotional process, they acknowledge that cognition and
emotion are intertwined and thus they conceptualise hope as an emotional response
which is creative and cognitively complex and they incorporate many cognitive
elements into their theorising.

Following from a constructionist stance towards hope, Averill, Catlin, and Chon
(1990) carried out qualitative and quantitative research aiming to identify the ‘rules
that bind hope’. The ‘rules’ identified reflected that: hope must involve realistic albeit
challenging goals and action towards the desired goal, hopes must be morally acceptable, and hopes must reflect peoples' priorities. Their findings regarding the 'morally acceptable' aspects of hope suggest a societal (and therefore culturally and historically based) role in determining what is considered 'acceptable' when it comes to hoping. This contrasts with Snyder et al.'s (1991) hope theory, which views hope as a cognitive and hence individual process and shifts the focus of hope from the individual to social and historical influences.

Furthermore, Averill and Sundararajan (2005) identified cultural differences in hope narratives between Western and Eastern cultures arising from Judeo-Christian versus Confucian and Buddhist influences respectively. According to them, Western cultures emphasise coping-based hope, which involves taking steps towards desired goals. This requires an accurate assessment of the situation in order to ascertain which course of action is required and is thus more externally focused. Conversely, Eastern cultures emphasise wish-based hope, which involves personal desire, irrespective of the attainability of the goals, and therefore is more introspective and reflective of the individual's yearnings than of the circumstances. In addition, Eastern cultures place more emphasis on moral and self-development aspects of their wishes, viewing hope as an enduring personal attribute rather than an episodic emotional response to a situation (Averill & Sundararajan, 2005).

Based on Averill and Sundararajan's (2005) findings, it appears that Snyder et al.'s (1991) conceptualisation of hope, which focuses on goal setting and coping, reflects Western rather than Eastern views of hope. While Western perspectives on hope emphasise unblocking goals, Eastern perspectives emphasise the development of personal attributes such as endurance and courage (Averill & Sundararajan, 2005). Therefore, hope as described by hope theory does not reflect important cultural differences which are relevant to therapeutic practice. For instance, while capitalising on problem-solving and optimism may be productive when working with a Western client, it would be more beneficial and culturally sensitive to focus on courage or fortitude with Eastern clients (Averill & Sundararajan, 2005).
Edey and Jevne (2003) stress that hope is subjective and personally constructed and thus, different people hold different views on what constitutes valid hope and experience hope differently. Therefore, it is essential that practitioners examine their own hope theories and histories, and their subjective constructions of hope, and how these impact on their practice (Edey & Jevne, 2003).

Working with Hope

*Implicit Hope*

In a modified grounded theory study on hope in bereavement counselling, Cutcliffe (2004, 2006a, 2006b) interviewed therapists operating from psychodynamic (psychoanalytic), gestalt, humanistic (person-centred) and eclectic approaches, as well as former clients, and identified one core variable and three sub-core variables. Cutcliffe (2004) termed the core variable the *implicit projection of hope and hopefulness*. The sub-core variables represent temporal stages of the process and consist of forging the therapist-client relationship and connection, facilitating a cathartic release, and enabling the client to experience a healthy (good) ending. Regardless of the therapeutic approach, both therapists and clients felt hope was an essential but implicit aspect of therapy and that it arises from the therapeutic relationship rather than from any deliberate intervention or intentional discussion of hope. Moreover, explicit attempts to inspire hope were viewed as counterproductive, as they could be perceived as an imposition of the therapists’ agenda. Rather, it was the therapists’ implicit belief that clients could reach a more hopeful position, and which permeated the therapy, which was believed to be beneficial.

A strength of this study is its focus on individuals in need of bereavement counselling, who represent a population in particular need of hope (Harvey, Orbuch, Weber, & Merbach, 1992), and which therefore lends itself well to the study and exploration of hope. In addition, it focuses on both therapists’ and clients’ perspectives, offering a more comprehensive view of hope in counselling. Although this theory arose from interviews with bereavement counsellors and clients, Cutcliffe (2004) suggests that
the processes described by his theory may apply to other client groups and serve as a building block for interventions with other populations.

An important point that emerged in Cutcliffe's (2004) research is that regardless of the therapists' theoretical orientation or techniques, it was the presence of certain personal qualities in the therapists that contributed towards the inspiration of hope. Indeed, Cutcliffe suggests it is the caring interpersonal relationship between therapist and client that allows hope to emerge. The importance of the quality of the therapeutic relationship to therapeutic outcomes is strongly supported by empirical evidence (Cooper, 2008). However, from Cutcliffe's (2004) perspective, hope is something that the therapist gives to the client "via a spiritual connection" (p. 178). This perspective not only places full responsibility for building and sustaining hope on the counsellor, thus rendering clients passive recipients of hope, but it attributes the growth of hope in clients to mystical and unclear forces. Cutcliffe (2004) suggests that hope is projected into the client via "indirect, osmotic-like" (p. 181) processes whereby the client 'soaks up' the therapist's emotions and hope from the hopeful atmosphere surrounding the counsellor, and via a spiritual or transpersonal connection through which hope flows from therapist to client. Therefore, the therapists' own hope in themselves and their abilities must be renewed and replenished in supervision and then projected into the client (Cutcliffe, 2004). This perspective stands in stark contrast to other conceptualisations of hope as something that can be worked on explicitly in therapy (e.g. Larsen & Stege, 2010b; Snyder, 1999), that is co-created (e.g. Weingarten, 2010), and that is influenced by multiple factors besides the therapist (e.g. Flaskas, 2007). Additionally, from this perspective, inspiring hope is not a two-way process. It is the therapist who inspires hope in the client. However, others argue that in a genuine therapeutic relationship, hope is a two-way process (e.g. Edey & Jevne, 2003). Although the therapist's role in building and maintaining hope is essential, placing all the responsibility for this on the therapist arguably puts the therapist under a lot of pressure, disempowers the clients and fails to acknowledge other potential sources of hope in the clients' lives.
Hanna (2002) also argued that hope can be built upon and transmitted from the therapist to the client in therapy, but that this must be done implicitly in order not to invalidate the client’s suffering (Hanna, 2002). However, Hanna proposes concrete ways in which this may be achieved in therapy, other than the therapist ‘projecting hope’ into the client (Cutcliffe, 2004). Firstly, Hanna (2002) emphasises the importance of acknowledging and reflecting the client’s hopelessness. In addition, Hanna (2002) recommends generating a variety of solutions for dealing with situations or problems: helping clients to identify qualities in themselves; empowering clients by reframing negative behaviours as skills and threats into challenges; helping clients to retell their story with a sense of hope; and examining core beliefs about the future (Hanna, 2002). Additionally, hope can be instilled by sharing stories of people with similar stories who have made positive changes and by exposure to others with similar problems (Hanna, 2002). For instance, Yalom and Leszcz (2005) argue that one of the strengths of group therapy is that witnessing others’ improvement and hearing their testimonies inspires hope because it makes change seem possible and goals seem attainable. Hanna (2002) adds that people can derive hope from other sources such as books, films, and speakers. This not only de-emphasises the role of the therapist as provider of hope, but highlights the relational, learned and flexible dimensions of hope (e.g. Dufault & Martocchio, 1985; Larsen & Stege, 2010b).

Explicit hope

There is a marked debate surrounding whether hope should be addressed implicitly or explicitly in therapy. While some advocate the importance of implicit hope, stressing that hope-focused interventions risk invalidating clients’ suffering and hopelessness (e.g. Cutcliffe, 2004; Hanna, 2002), others argue that it is possible to explicitly address hope in therapy without pushing the therapists’ own agenda and without being insensitive to the clients’ distress (e.g. Edey & Jevne, 2003; Larsen et al., 2007; Larsen & Stege, 2010b).

Edey & Jevne (2003) argue that, although hope usually operates as a silent factor in counselling and is seldom explicitly addressed, sometimes moving it to the foreground
can give direction and power to the therapy. They describe several possible ways of using hope explicitly in therapy and emphasise the importance of language for hope-focused counselling. For instance, they propose using hope-focused questions (e.g. What is it that threatens your hope when you look to the future? or What would be the smallest change that could increase your hope?), or common scaling questions, to invite clients to an explicit focus on hope and an exploration of their hope experiences (Edey & Jevne, 2003; Larsen et al., 2007). In addition, Edey & Jevne (2003) highlight three linguistic tools therapists can use to convey hope. These involve using the words when (e.g. when you learn to manage your anxiety), yet (e.g. you haven’t learned yet), and I believe (e.g. I believe you can learn to manage your anxiety). Similarly, image-based interventions, such as making collages or asking the client to choose a picture that reminds him/her of hope and keeping it in a prominent place, offer ways of addressing hope explicitly in therapy (Edey & Jevne, 2003; Larsen et al., 2007).

Larsen et al. (2007) view hope as functioning on an implicit/ explicit continuum and argue that addressing hope both implicitly and explicitly provides more therapeutic options and is more useful than favouring one approach. Interestingly, Larsen et al. (2007) view hope as a conversational process rather than an outcome or a goal of therapy (unlike Snyder et al. 2005). Larsen and Stege (2010a; 2010b), using a qualitative case study methodology, interviewed psychotherapists who had received some sort of hope-focused education and explored their use of implicit and explicit hope interventions. The in-session focus of the study, reviewing recorded sessions and obtaining practitioners’ reflections on their interventions, offers a new perspective on how therapists understand and practice hope. It was found that hope was addressed by therapists both implicitly and explicitly within therapy sessions. Two key themes were identified within the implicit hope category: the therapeutic relationship and client perspective change. Specifically, therapists identified: witnessing client hopelessness; highlighting client resources; and perspective change via reframing, metaphors, humour, and externalising, as ways of actively, yet implicitly, engaging with hope in therapy (Larsen & Stege, 2010a). Larsen and Stege’s (2010a) findings also emphasise
the importance of the therapeutic relationship to the development of hope. However, rather than creating a hopeful atmosphere and transplanting hope from therapist to client as Cutcliffe (2004) described, hope is engaged through language, whether implicitly or explicitly. In terms of explicit hope-focused interventions, therapists focused on different dimensions of hope, i.e. cognitive/goals, behavioural, emotional, relational and temporal (Larsen & Stege, 2010b). In addition, they enquired about threats to clients’ hope and hoped-for ways of being and provided clients with some hope-related psychoeducation. However, it must be noted that the study focused on therapists with formal training in hope, which is uncommon and which is likely to have impacted on their use of hope-focused interventions. In addition, client experiences and therapeutic outcomes were not reported.

Larsen et al. (2007) interestingly highlight that during the process of therapy, both therapists and clients can approach hope implicitly or explicitly in different combinations (i.e. both can approach it implicitly or explicitly, or the client may be implicit while the therapist is explicit and vice versa), highlighting that both approaches are useful to therapeutic work, that clients and therapists may approach hope differently and that these approaches may shift across the therapy.

'Reasonable hope'

Weingarten (2010) distinguishes between hope and ‘reasonable hope’, based on whether what is hoped for is attainable or unattainable, and proposes that this distinction has implications for clinical practice. Weingarten argues that what distinguishes ‘reasonable hope’ from hope is that hope is future oriented and involves waiting for a positive outcome, while ‘reasonable hope’ focuses on the here-and-now and making sense of one’s circumstances. In addition, Weingarten views hope as involving “feelings one may or may not be able to summon” (Weingarten, 2010, p. 7) while “reasonable hope refers to actions that one takes” (Weingarten, 2010, p. 7). Although distinguishing between attainable and unattainable goals seems undoubtedly helpful when establishing or adapting goals, Weingarten’s belief in the value of establishing what constitutes ‘reasonable’ or “sensible and moderate” (p.7) hopes
seems very subjective and therefore, caution must be taken in order not impose one’s subjective belief of what is reasonable or sensible but to carefully explore the attainability of goals with each individual client.

Reasonable hope has five characteristics: it is “relational; consists of a practice; maintains that the future is open, uncertain and influenceable; seeks goals and pathways to them; and accommodates doubts, contradictions and despair” (Weingarten, 2010, p. 8). Weingarten (2010) argues that while the dominant discourse of hope paints it as an individual attribute, or a feeling achieved by an individual, ‘reasonable hope’ is ‘done’ with others and flourishes in relationships. Weingarten (2010) argues that ‘reasonable hope’ is a practice in the sense that it involves deliberate movement towards a goal and focuses on hope as a process rather than an outcome. Additionally, acknowledging that the future is not determined opens new opportunities for change which helps to instil hope and counter hopelessness. ‘Reasonable hope’, in line with Snyder et al.’s (e.g. 2005) hope theory, seeks goals and pathways, accepting that these may need to be continually reassessed and downscaled towards less ideal but more attainable ones. Finally, Weingarten argues that a key strength of ‘reasonable hope’ is that it makes clients less vulnerable to hopelessness by offering a middle ground between hope and despair and recognising that hope and hopelessness coexist. This makes ‘reasonable hope’ more robust and easier to sustain, as it can withstand contradiction, unlike hope which exists in all or nothing categories (Weingarten, 2010).

Although Weingarten (2010) writes from a systemic perspective, the five characteristics of ‘reasonable hope’ are argued to be useful across therapeutic modalities. Weingarten (2010) highlights that helping clients to overcome hopelessness can be life-saving and argues that, through ‘reasonable hope’, therapists can increase their ability to bear witness to their clients’ suffering and help to co-create hope with them. Through ‘reasonable hope’, the role of the therapist shifts from attempting the often impossible and discouraging task of instilling hope in clients, to creating a conversational space where ‘reasonable hope’ can be co-created
From this new position, the role of the therapist involves witnessing from an aware and empowered position, identifying and working with trauma in order to counter the resulting fear and hopelessness, creating conversational hope spaces, identifying sources of resilience available to the client and identifying barriers and supports for 'reasonable hope' (Weingarten, 2010).

Weingarten (2010) argues that therapists who want to co-create 'reasonable hope' with clients must convey three main ideas to them: firstly 'reasonable hope' is not a feeling but a course of action. Secondly, uncertainty and hopelessness co-exist with hope. And finally, because hope is relational, others can contribute towards the goal, pathways and action stages of it (Weingarten, 2010). According to Weingarten (2010), therapists must develop a repertoire of questions aiming to raise their clients' awareness of these key concepts during therapeutic discussions. Thus, Weingarten advocates an explicit use of hope by therapists, with the objective of co-creating hope through language.

**Existential hope**

Adopting a temporal and existential perspective, Stone (1998) describes hope as the "anticipation of the future, a feeling that one's troubles can end or will at least become manageable, a recognition of possibilities that lie ahead, an investment in a future that holds promise" (p. 432). He argues that hope and hopelessness can be understood through Kierkegaard's description of individuals as possessors of actuality, freedom and possibility, which refer to our past, present and future respectively. From this perspective, Stone (1998) argues, hopelessness can be understood as resulting from individuals allowing "their actuality (past) to limit and dominate their possibility (future) by not exercising their finite freedom in the present" (p. 433). He recommends exploring exceptions, reframing, focusing on client strengths and developing future goals as effective means of shifting the focus away from a hopeless past and instilling hope for the future. Similarly, Jenmorri (2006) emphasises the importance of the existential themes of hope and despair in trauma therapy and the value of conjoint meaning making, through the creation of personal narratives that enable the emergence of hope for both clients and practitioners.
Hope and Hopelessness

Balancing Hope and Hopelessness

The concept of hope and hopelessness co-existing rather than constituting opposite experiences is important and has implications for practice and for how clients integrate hope and hopelessness into their lived experiences. It can also help clients to redefine their expectations regarding hope, thus preventing the formation of unrealistic goals and their subsequent disillusionment (Nell, 1972).

Flaskas (2007) argues that hope and hopelessness do not exist in inverse proportion to each other. Instead human experience is characterised by the coexistence of hope and hopelessness in a dialectical relationship (Flaskas, 2007). Flaskas (2007) emphasises the therapeutic importance of recognising the coexistence of hope and hopelessness in clients and ourselves and of therapy orientating to the balance of hope and hopelessness in clients' cognitive, emotional and behavioural experiences. Additionally, practitioners should be aware that hope can be experienced differently at these different levels, as this can provide opportunities for intervention e.g. a client can be encouraged to take hopeful actions even while not feeling hopeful. Additionally, Flaskas (2007) argues that these levels constitute a 'constellation' of experiences which is influenced by complex social and relational contexts and resources and by different experiences and expressions of hope and hopelessness. From this perspective, it is the balance in experiences of hope and hopelessness that therapy should focus on. This provides a more complex and multilayered conceptualisation of hope that requires the therapist to take into account wider processes beyond the client-therapist relationship, including individual, family, social and historical processes and to focus on the complex dynamics of hope and hopelessness. Importantly, Flaskas (2007) warns that therapists should witness and hold hopelessness as well as hope in the therapeutic relationship and avoid the tendency to "default to 'practices of hope'" which can constitute "a defence against engaging with the constellation of hope and hopelessness" (p. 200).
The work of despair

Authors caution therapists against neglecting the importance of hopelessness and focusing on hope as a form of defence, with subsequent interferences in the therapeutic process. Some stress the importance of hopelessness as a precursor to hope within the actual therapeutic process. For instance, Babits (2001) refers to the death and resurrection of hope within therapy as the “Phoenix juncture”. According to Babits, sometimes in therapy hope can undergo a symbolic death, where it appears that no change or progress is possible, especially with difficult clients. Babits emphasises that in order for hope to be transformed or reborn (as the mythological bird was) it is essential that the therapist articulate his/her own feelings of hopelessness in the process. This intervention, she argues, goes beyond mirroring and actually helps the therapist to establish contact with the client by validating the client’s ability to evoke a human response and reducing client isolation by sharing and understanding the hopelessness. The role of the therapist involves acknowledging and containing the client’s hopelessness when a client is within the “Phoenix juncture”, in order that hope can ‘rise’ from its ashes.

The Negative Side of Hope

Some authors focus on the imbalance of hope and hopelessness, with negative repercussions where ‘excessive’ hope is involved, or where hope becomes destructive. Babits (2001) outlines the distinction between hope and ‘problematic hope’ drawing from a psychoanalytical developmental perspective. From this perspective, problematic hope is seen as regressive, arising from the paranoid-schizoid position and related to the rejection of reality, whereas adaptive hope is seen as arising from the depressive position and longing for an object beyond one’s control. Without the necessary developmental foundations, Babits argues, adaptive hope cannot emerge. Therefore, therapy with clients who have not been able to develop adaptive hope involves helping clients to move out of the paranoid-schizoid position and laying the foundations for adaptive hope to develop (Babits, 2001).
On the other hand, Omer and Rosenbaum (1997) argue that although psychotherapists know that hope is adaptive and that relinquishing hope may be counterproductive, hope can also become a destructive coping mechanism, even if the object of hope is not false or unrealistic, when: “(a) it leads to a disparaging attitude towards the present, (b) it is mindless of sacrifices, and (c) it hampers flexibility” (p.226). Therefore, sometimes the work of despair (i.e. relinquishing hope) is necessary in order to achieve wellbeing.

Importantly, Omer and Rosenbaum (1997) argue that hope can be “diseased in itself, in its very process and mechanism” (p.226). For instance, ‘diseased hopes’ focus on a better past or future, thus neglecting the present, mindlessly forsake things in pursuit of the hope, and neglect alternatives, not leaving room for new hopes (Omer & Rosenbaum, 1997). Therefore, Omer and Rosenbaum (1997) argue that, should the therapist detect that the client is harbouring ‘diseased hopes’ (such as those discussed above), the work of despair may be a necessary therapeutic process. However, this medicalised perspective of hope does not take into account the underlying function or meaning of the ‘diseased’ hope for the client and forecloses an exploration of the client’s phenomenological experience of hope. Additionally, they do not clarify how therapists are meant to ‘detect’ ‘diseased hopes’. Whether therapists are able to assess such a thing is questionable. Furthermore, pathologising types of hope does not seem necessary or helpful in order to work with hope therapeutically.

Omer and Rosenbaum (1997) also distinguish between becoming resigned and giving up hope. According to them, while becoming resigned involves passively accepting something one doesn’t want, giving up hope is active, and involves striving to “kill and bury the enemy of our peace” (p. 232). Although giving up hope is a painful process, it is only by giving up illusions of what ‘should’ be, that clients can shift their focus from the future to the present where they can take action and live their lives more fully (Omer & Rosenbaum, 1997). Similarly, Bergin and Walsh (2005) argue that false hopes are damaging to the client because they impede individuals from pursuing realistic rather than unattainable goals and from accepting that negative
outcomes may or will occur. Additionally, they warn that false hope can develop into denial.

Nell (1972) speaks of the 'hopelessness of hope' that characterises many 'substance abusers', 'neurotics' and 'psychotics', whose hoping prevents them from applying themselves to therapy. He distinguishes between well-founded hopes or reasonable expectations which "generally involve facts and goal-directed activity" (p. 60) and unfounded hope which often becomes a substitute for action and responsibility leading to "fatalistic passivity" (p. 60). Therefore, Nell (1972) argues, hope can serve as an avoidance mechanism: to avoid seeing the reality of a situation, to avoid action, or to avoid taking responsibility by waiting for 'magic' solutions. Nell (1972) warns that in instances where hope serves any of these purposes, the inevitable outcome will be hopelessness. However, while unrealised hopes lead to hopelessness, Nell (1972) argues, denied hope (i.e. challenging unfounded hope) can lead to the mobilisation of one's resources and thus to self-actualisation. Similarly, Horowitz (2008) stresses the value of individuals with long-term mental illness accepting limitations and experiencing disillusionment and frustration as precursors to identifying what is actually attainable for them. Therefore, challenging unfounded hope would be a necessary therapeutic intervention in order to replace unattainable hopes with attainable ones.

Research also suggests that regardless of therapeutic approach, client hope and expectations are associated with therapeutic outcomes and that, just as unrealistic or false hopelessness may prevent a client from engaging in therapeutic work (Edey & Jevne, 2006), excessively high or overoptimistic hopes for therapy are related with poorer outcomes. Therefore, the client must be encouraged to adopt more realistic expectations (Cooper, 2008).

However, Jevne (2005) stresses that false hope and despair are subjective and personally constructed and points towards the debate around "contested hope" (Simpson, 2000, pp. 152-153), which acknowledges that different people hold
different views on what constitutes valid or false hope. Additionally, she stresses the importance of practitioners examining their hope theories and histories and their subjective constructions of hope and how these impact on their practice and notion of what constitutes legitimate hope.

Summary

Hope-related research has expanded in the last thirty years (Elliott, 2005) and there is increasing theory suggesting the therapeutic importance of hope to diverse populations including older adults (Bergin & Walsh, 2005), the bereaved (Cutcliffe, 2004), families (Flaskas, 2007) and couples (Ward & Wampler, 2010). However, most hope-focused research consists of nursing studies focusing on hope in chronic and terminal illness (e.g. Elliott & Olver, 2009; Harris & Larsen, 2007).

In terms of practical applications of hope within therapeutic settings, current hope literature is at an early stage and focuses predominantly on developing frameworks and conceptualisations of hope and its use in therapy. While the importance of the therapeutic relationship is emphasised across therapeutic approaches, hope has been conceptualised from different perspectives (e.g. emotional, cognitive, behavioural etc.), and there is a lack of consensus regarding the focus on specific dimensions or the multidimensionality of hope. Furthermore, there is a lack of consensus regarding the implicit and explicit uses of hope in therapy, and the beneficial and detrimental effects of hope and hopelessness. These distinctions have a bearing on practice in terms of the different levels at which interventions can be targeted and the availability of intervention opportunities. However, these frameworks and conceptualisations are mostly derived from practice and are primarily retrospective and/ or anecdotal. Indeed, there is a dearth of empirical evidence linking theory with counselling and psychotherapeutic practice and of research on the effectiveness of different interventions with different client groups (Cutcliffe, 2009).
Implications for counselling and psychotherapeutic research and practice

There is a need for the generation of cumulative and integrated knowledge to enable the development of a solid theory of hope which can serve as a building block for hope-focused interventions (Cutcliffe, 2009). Additionally, there are significant gaps in the literature that must be addressed. Recently, qualitative studies exploring ways of using hope in therapy and attempting to generate theory on hope work with different client populations have begun to emerge (e.g. Cutcliffe, 2004; Larsen & Steg, 2010a; 2010b). For instance, Larsen and Stege's (2010a, 2010b) study is one of the few studies to explore therapists' explicit use of hope in therapy. However, the study focused on therapists with formal training in hope whose interventions may differ from those of other practitioners. Reducing hope in this way and focusing on explicit uses of hope arguably strips hope from its context, meanings and interaction with other therapeutic factors. Moreover, client experiences and therapeutic outcomes were not reported. Indeed, few studies have explored clients' experiences and accounts of hope in therapy and thus, existing studies remain predominantly practitioner focused.

Additionally, there is scant research on cultural and ethnic differences and similarities with regard to hope and its implications for therapeutic practice. Some potentially relevant differences between Eastern and Western cultures have been identified (Averill & Sudararajan, 2005), while Chang and Banks (2007) found no significant differences in terms of hope between European Americans and other racial/ethnic groups living in America. However, these findings are not specific enough to guide or inform practice with clients from different cultures, faiths, or ethnic backgrounds. Cutcliffe (2009) suggests that there may be common psychosocial processes for promoting hope across different client groups, as well as group specific processes. An exploration of shared and specific hope processes, conceptualisations of hope and lived experiences of hope would help to develop hope theory that accounts for cultural and developmental variation and to inform cross-cultural interventions.
Conclusions

This paper has offered a review of the extant literature regarding different conceptualisations of hope and their therapeutic implications. Although different hope-focused interventions have been proposed in the literature, these lack empirical support and there is no coherent framework to support and inform the use of hope in counselling and psychotherapeutic interventions. Hope research in the context of therapy is still at an early stage and further research addressing the uses of hope with different client populations and evaluating the effectiveness of hope-focused interventions is required in order to inform practice.
"Those who know how close the connection is between the state of mind of a man - his courage and hope, or lack of them - and the state of immunity of his body will understand that the sudden loss of hope and courage can have a deadly effect" (Frankl, 1962).

My interest in understanding hope, what it is and what it is not, when it is beneficial or not and when, how and with whom ‘hope work’ is helpful, is both personal and professional. My interest in the therapeutic value of hope arose as a result of my personal therapeutic journey and as a result of trying to understand the role that hope played in the lives of friends who were suffering from chronic or degenerative physical or mental illness. I was intrigued as to how it was possible to journey from hopelessness to hope, learn to live with hopelessness and not lose hope facing circumstances that are not likely to improve or that will get progressively harder. I am interested in learning how therapists can help to instil, preserve and nurture hope in clients whose lived experiences and circumstances have compromised their ability to fight hopelessness.

I believe that hope is one of the foundations of any psychotherapeutic work: the client who seeks therapy is hoping for something and the therapist hopes to help the client in some way. In setting therapeutic goals, both client and therapist hope that these will be achieved. I became interested in how hope can be instilled and maintained in the therapeutic context where clients often suffer from hopelessness as a result of facing acute or chronic adversity which have undermined or depleted their ability to hope. I chose this topic because I wanted a chance to develop a deeper and broader understanding of hope and how it could inform my practice. Witnessing how different people ‘did hope’ differently and the different roles that hope and its effects had in their lives through their changing circumstances helped me to realise that, as with many things, there is no one-size-fits-all theory, model, or intervention when it comes to hope.
Living with chronic and degenerative physical and mental illnesses is a daily struggle and one that requires a constant balancing of hope and hopelessness and a constant readjustment of hopes for oneself and one's future. Although each 'hope story' I am familiar with is different, in my view, each one reflects how hope is essential to wellbeing and to the willingness not to give up. I experienced depression for several years, it was a period where hopelessness and desperation set in and I lost hope that things could ever improve and the physical and mental health impact of this loss of hope was devastating at times. Similarly, observing and journeying with my loved ones through illness, I began to see that, at times, the loss of hope was unavoidable. It occurred periodically when having to come to terms with the losses and limitations entailed by lived experiences or by illness. Sometimes hopelessness arose when 'false' hopes where unmasked and they were forced to face the harshness of their circumstances. Without hope serving as a buffer, depression would often set in. However, in other cases hope would shift and something new to hope for would be found and so, although hope changed constantly it was ever present and infused them/us with the will to keep going. At other times though, hope can merge into denial and stop people from taking the necessary action to improve their circumstances, or at least avoid or slow down the deterioration of their illness. In this respect, hope can be as damaging as hopelessness. As a friend, relative or therapist, it is often hard to distinguish what constitutes hope and what constitutes denial and it is a delicate business to try and make someone be more 'realistic' when their reality is so harsh that accepting it may be too much for them to withstand and may annihilate hope. Indeed, hope often serves as a coping mechanism and as a buffer against reality and this has both positive and negative implications. My engagement with the literature review helped me to think about hope in different ways and I found it personally useful to read others' views about unhelpful hope. For instance, I began reflecting on the function of hope and on short vs. long-term outcomes, e.g. hope can keep someone's morale up through repeated health crises. However, it can also prevent the person from taking necessary action while they await a miracle cure or solution. In this respect, colluding with 'false' hope can be damaging and, in the context of practice, sabotage the therapeutic process.
This argument revolves around the assumption that an individual can hold the truth and an accurate perspective of ‘reality’ while the other doesn’t and that not being ‘realistic’ is somehow damaging to the individual. However, while writing this paper, I became increasingly aware of the error in that assumption and my own mistaken assumptions and of the lack of consensus regarding what constitutes ‘false’ and ‘realistic’ hope. These concepts are subjective and individually determined. In addition, it became apparent that in some cases, challenging people’s ‘denial’ in order to help them reach some level of ‘realistic acceptance’ is not beneficial and can actually be destructive.

As a result of this review, my purpose in understanding hope is not to be able to place clients in a category, give their hope a rating, or try to impose a right/realistic perspective of hope on them. This research has helped me to view hope as subjective and constructed and as a multidimensional phenomenon which I have found hope-affirming, as being mindful of the different dimensions offers more angles from which to conceptualise and work with hope. My hope is that in learning about specific ways of working with hope, I will be better equipped to make sense of my own and others’ lived experiences, to learn to balance hope and hopelessness and to find a repertoire of ways in which to face challenges to hope in therapy with flexibility and creativity.
APPENDIX A – SHORT BIOGRAPHICAL NOTE

Prior to her involvement with Psychology, the author studied Marketing and PR and worked in the industry before realising that her real passion lies in helping others to develop and fulfil their potential. Isabelle studied Psychology at the University of Bath, took counselling courses at Harvard University and is currently completing a Doctorate in Psychotherapeutic and Counselling Psychology at the University of Surrey. In terms of research and practice, she has a particular interest in long-term health conditions and different approaches including Mindfulness and Acceptance and Commitment Therapy (ACT).
APPENDIX B – COUNSELLING PSYCHOLOGY QUARTERLY INSTRUCTIONS FOR AUTHORS

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Research Report 1:

‘Living with chronic illness: A Grounded Theory study of adapting to chronic illness when diagnosed when young’.

Abstract

Objectives: To explore the subjective views of people who were diagnosed with a chronic illness when they were young, so as to widen an incipient body of qualitative literature around the experience of living with chronic illness.

Method: Taped, in-depth, semi-structured, qualitative interviews with six young women were transcribed verbatim and analysed using Grounded Theory methodology.

Results: A theoretical understanding was developed of the experiences of people who were diagnosed with a chronic illness when they were young. The core concept described the experience of chronic illness as progressing towards a new normal and was related to three, interrelated, higher-order categories which were labelled new body, new life and seeking information.

Conclusions: This study contributed towards the development of a theoretical framework with which to understand how people who were diagnosed with a chronic illness when they were young adapt to living with chronic illnesses. Insights are provided into how illness influences their identity and development and potential clinical implications are discussed.

Keywords: chronic illness; young; grounded theory; qualitative.
Introduction

Chronic illnesses are illnesses which are, at present, incurable and they are currently the leading cause of mortality, morbidity and disability worldwide (World Health Organisation (WHO), 2002). Medical advances allow many of these illnesses to be controlled to varying degrees, thus reducing the number of previously fatal illnesses and increasing life expectancy. However, as the incidence of chronic illness increases with age, increased life expectancy also means an increase in the likelihood of developing one or several chronic illnesses. Indeed, the incidence of chronic illnesses is increasing globally and is expected to be the main cause of disability by 2020 (WHO, 2002).

Chronic illnesses vary greatly in terms of symptoms, severity and progression. They can profoundly impact on essential life domains including education, employment, financial opportunities, social, family and romantic relationships (Lubkin & Larsen, 2006) and sexual functioning (Nusbaum, Hamilton & Lenahan, 2003). Many people with chronic illnesses may often also experience psychosocial distress, including body image dissatisfaction (Benrud-Larson et al., 2003), anxiety, depression, cognitive strain, social isolation and adverse effects on self-esteem, self-concept and interpersonal relationships (Lubkin & Larsen, 2006). Additionally, chronic illness often involves adapting to an altered body, an uncertain future, a restricted life and feeling like a burden (Charmaz, 1983). Regardless of the illness, being diagnosed with a chronic condition is usually life-changing, requiring the individual to learn to: recognise and manage symptoms; deal with illness flare-ups or exacerbations; use medication, treatments and services effectively; and develop strategies to manage the psychosocial consequences of the illness (Department of Health, 2001). Indeed, the challenges faced by someone with a chronic illness are complex and continuous and therefore require the individual to adapt constantly to developing symptoms and circumstances. More so in cases where the illness is degenerative and individuals face the prospect of increasing disability, disease progression and an uncertain future.
Given the early onset of some long-term conditions, the individuals who are diagnosed with them usually face a lifetime of illness. Additionally, they must negotiate more life stages and have more time ahead of them to adapt to living with the illness and to managing symptoms than someone older with a shorter life expectancy. It is estimated that 20-30% of adolescents in Western countries have chronic conditions (Yeo & Sawyer, 2005) which can negatively affect their functioning and autonomy at a stage where increasing independence is the developmental goal. Furthermore, an early diagnosis adds new facets to the social, biological, psychological, cognitive, and cultural challenges faced by young people as they navigate through adolescence and into adulthood (Boice, 1998). For instance, research suggests that young people with chronic conditions are at increased risk of mental health disorders, risk-taking behaviours and poor compliance with medication (Burns, Sadof & Kamat, 2006), as well as psychological difficulties such as body image (Larouche & Chin-Peuckert, 2006) and self-concept issues (Ferro & Boyle, 2013). Adolescents face developmental challenges such as the development of sexuality, independence, social identity, personal identity, body self-integrity and self-image as well as increasing responsibility for managing their conditions (Burns, et al., 2006; Sawyer, 2009). However, whilst managing a chronic condition while negotiating the transition into adulthood poses many challenges, it is not always an entirely negative experience. For instance, it can help young individuals to develop as a person, become more empathic or draw families together (e.g. Eiser, 1993; Venning, Eliott, Wilson, & Kettler, 2008), adding another layer of complexity to their experience.

Managing a chronic illness while progressing through different life stages may have implications for the fulfilment of developmental milestones and rites of passage (Morgan, Davies, Palmer & Plaster, 2010), and for individuals’ experiences of illness which could inform theory and counselling psychologists’ therapeutic work with this client group. For instance, a diagnosis of chronic illness early in life could potentially impact on individuals’ experiences of navigating different life stages and how they develop or construct their identity and sense of purpose (Erikson, 1963).
Consequently, living with a chronic illness may influence the development of individuals’ interpersonal relationships (Hurtig & Park, 1989), their social identities, and how they experience their place in society (Tjafel & Turner, 1979). Iyer, Jetten, and Tsivrikos (2008) emphasise that life transitions usually involve changes to people’s identity and group membership. Indeed, being diagnosed with an illness early in life may also impact positively and negatively on young people’s developing sense of belonging to different social groups, identity processes and how their sense of function and meaning progress over time (Olsson et al., 2003).

Developing a chronic illness early in life usually results in the individual having to navigate more life stages while dealing with their illness and having more time for their perception of illness to develop, to adjust to changes in their life and to develop coping strategies. Retrospective accounts of what such processes entail could provide valuable insights to develop theory with which to inform therapeutic practice (Morse, 2001). Research so far has focused on the impact of chronic illness on young people and their families (Miles & Holditch-Davis, 2003). However, existing research tends to be quantitative and from epidemiological, sociological or nursing/medical perspectives. Miles and Holditch-Davis (2003) have stressed the need for in-depth person-centred, as opposed to variable-focused, research in order to enhance the quality of research. Similarly, Van Houdenhove (2002) underlines the valuable therapeutic clues which can be obtained by taking account of participants’ autobiographical stories. With regard to qualitative studies, which aim to provide a more in-depth understanding of phenomena, research has explored: parents’ and children’s perspectives on illness and hospitalisations (Sartain, Clarke & Heyman, 2000) and on adapting to illness (e.g. Gannoni & Schute, 2009); parental perspectives on young people’s chronic conditions (e.g. Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009; Sallfors & Hallberg, 2003); and young people’s perceptions of illness and its impact on their daily life (Capelli et al., 1989; Venning et al., 2008) and the emotional and physical challenges they involve (Woodgate, 1998). Jelbert, Stedmon and Stephnes (2010) explored retrospective accounts and identified common shared experiences amongst adolescents who had recovered from CFS. However,
research which adopts a psychological perspective or aims to inform psychological theory or practice is scarce.

Eiser (1993) stresses the importance of understanding, not only the psychological impact of illness, but how individuals’ perspective of the illness and its impact develops over time. Similarly, Kralik, Paterson and Coates (2010) emphasise the importance of acknowledging that over time, people living with chronic conditions develop “considerable experience and a level of expertise in managing their conditions” and that “this needs to be recognised and built upon in order to support wellbeing” (pp. 45-46). Although there is some research on children’s developing perspective of their conditions (e.g. Christian & D’Auria, 1997), there is scant research exploring the perspectives of adolescents or of people who were diagnosed during adolescence. Successful and relevant interventions require a better understanding of how people who were diagnosed when they were young make sense of their experiences and adjust to them. Therefore, an exploration of chronic illness from the unique perspective of people who were diagnosed when they were young could shed a light on significant processes such as: their learning and adjustment processes, useful and required resources for living with illness, salient/relevant experiences, and the insights gleaned over the course of their illness, in order that we can better understand and help individuals facing similar challenges to manage their changing needs and the lasting implications of their conditions for their development.

Additionally, following a systematic review of psychosocial interventions for adolescents and young adults with chronic conditions, Samson-Daly, Peate, Wakefield, Bryant, and Cohn (2012) stress the need for intervention development which is grounded in theoretical frameworks. However, since many of the more common chronic illnesses affect mainly adults and older adults, there is not a wide breadth of research or a body of theory describing how people who are diagnosed when they are young experience chronic illness and how they adapt to the changes brought about by their illness in order to progress through life in a personally satisfying way. Therefore, a richer understanding is required of the relationship
between different aspects of the experience of being diagnosed with a chronic condition when young and of the different processes involved and how they change over time. This could contribute towards the development of a theoretical framework with which to understand the experiences of people adapting to chronic illnesses.

In light of the above, the aim of this research was to explore the subjective accounts of people who had experienced chronic illness since they were young, with the objective of contributing towards the development of a theory about living with chronic illness. A qualitative perspective was deemed suitable for this research, as it enables meanings, processes, contexts and unique personal accounts to be explored in detail, yielding new and in-depth insights into the experiences of people who were diagnosed with chronic illnesses when they were young. The study adopted a Grounded Theory (GT henceforth) approach to data collection and analysis. GT aims to develop theory which explains and describes processes and relationships. Given the dearth of research that accurately describes the experiences of people who were diagnosed when they were young and the need to develop a deeper understanding in this complex area, a methodology with an emphasis on generating theory was deemed appropriate. GT is an inductive qualitative methodology, which aims to explore phenomena without preconceived ideas, in order that the theory developed emerges directly from the data and is not distorted by the researcher’s assumptions (Charmaz, 2006; Glaser & Strauss, 1967). GT follows a theoretical sampling strategy to data collection (Charmaz, 2006). This involves recruiting participants who will enable the properties of the categories identified in the data, which constitute the emerging theory, to be more fully explored and developed. The analysis of the data was influenced by Charmaz’s (2006) social constructivist version of GT, which stems from the interpretive tradition. From this standpoint, both data and analyses are social constructions co-created by the participants and researchers and influenced by their relationship, experiences, values, preconceptions and contexts. The purpose of the analysis was to identify or develop key concepts/categories and their properties, linking relationships between them, to clarify the processes underlying the participants’ experiences of chronic illness, while remaining grounded in their
accounts. In order to develop the current theoretical understanding of the experiences of people who were diagnosed with chronic illnesses when they were young, this research asked: What are the experiences of people diagnosed with chronic illnesses when they were young?

Method

Participants

Six women with chronic illnesses aged 24-44 years who were diagnosed when they were young (mean = 24 years) participated in this study. The mean age of the sample was 35, with a range of disease duration of 2-19 years. The women’s diagnoses were systemic sclerosis (n = 3), fibromyalgia (n = 1), rheumatoid arthritis (n = 1), and ME/CFS (n = 1). Three participants were White European, one African American, one White American and one AfroCaribbean. Two participants were single and lived alone, one was separated and lived with her parents and three were married and lived with their spouse (one had a child). Four participants were university graduates and two had specialised training after secondary school. Two participants had part-time jobs, two had full-time jobs, one was in training and the other was unemployed and receiving disability allowance.

Following a theoretical sampling strategy, a person with chronic illness who was diagnosed when she was young was interviewed about her experiences with chronic illness. This participant’s experience served as a starting point for the identification and development of further interview questions and the recruitment of further participants. Subsequent participants were selected following a snowballing technique (i.e. from the participants’ recommendations). Successive selection criteria were data driven, i.e. subsequent informants were recruited based on the information, categories and leads that arose from the data (i.e. theoretical sampling). In grounded theory, this process is usually carried out until theoretical saturation is achieved (i.e. no new properties emerge from the interviews and analysis) (Charmaz, 2006; Glaser &
Strauss, 1967). However, owing to time constraints, reaching theoretical saturation in this study would not be viable. Therefore, this study aims to achieve ‘theoretical sufficiency’, whereby data collection is carried out until a sufficient theoretical account can be created from the data (Dey’s, 1999).

**Ethical considerations and confidentiality**

The researcher and her supervisor consulted the ethical flowchart published by the University of Surrey’s Faculty of Arts and Human Sciences (FAHS) Ethics Committee. It was decided that ethical approval would be required from the committee because, owing to the participants’ health conditions and to the personal nature of the research, the participants were considered vulnerable and the questions in the interview schedule could be deemed to be sensitive or offensive. The study obtained a favourable opinion by the committee (see Appendix A). Participants were informed of the purpose of the study. They were told that they may experience emotional distress during and after the interviews as a result of sharing their experiences, that their participation was voluntary and of their right to withdraw from the study at any time (see Appendix B). Written, informed consent was obtained from all of the participants (see Appendix C) and following the interview, participants were provided with a debrief form explaining the purpose of the research and providing contact details for the researcher and supervisor and for possible sources of support (see Appendix D).

Furthermore, as the study was based on a small sample and a snowball sampling strategy was used, any information which could reveal the participants’ identity (including the names of illnesses, locations, careers, etc.) was altered in order to protect their confidentiality and anonymity. Additionally, as the initial participant was an acquaintance of the researcher, voluntary participation, the right to withdraw without consequences and confidentiality were emphasised.
Procedure

Data was gathered from in-depth semi-structured interviews lasting 40-60 minutes. Interviews were recorded, transcribed verbatim, analysed and compared at each analytical stage. Additionally, memos (i.e. analytic notes) were written throughout the analysis (Charmaz, 2006). Participants were initially provided with a short demographic questionnaire (see Appendix E). The first interview was exploratory and consisted of the research question and a few general open-ended questions/probes (e.g. “What does it mean for you to have experienced X illness?”) (see Appendix F). The purpose of the questions was to encourage the participant to provide a detailed description of their personal experiences regarding their illness, their experience to date, how they managed the illness and what having an illness meant to them. Given the chronicity of the illness, a question on how they saw themselves in the future was also added.

As the theory began to emerge, interviews became more focused. For instance, the initial stages of the illness appeared significant and so a question focusing specifically on the initial stage was added to the schedule (e.g. “What was your experience like in terms of symptoms emerging, arriving at a diagnosis and starting treatment?”). Additionally, as tentative categories developed and participants provided new information, questions were added to explore these in more detail. For example, questions related to learning about the illness were incorporated when this emerged as an important aspect of the participant’s experience (see Appendix G). [See appendix H for a sample interview transcript].

Credibility

The researcher has attempted to contextualise the sample, provide a clear and coherent account of the research process and to provide extracts from each participant to illustrate each point in line with Yardley’s (2008) criteria for validity and quality in qualitative research.
Analysis

A GT approach as described by Charmaz (2006) was adopted to analyse the data. Data analysis consisted of two stages: initial coding and focused coding. The initial codes were mainly *in vivo* (i.e. in the participant’s own words) and/or gerunds (action words) that name and describe what is happening in the data.

Focused coding involves selecting and using the most significant/recurring initial codes to sift through the data and synthesise it into more abstract categories. The constant comparison method of analysis, whereby the data, codes, categories and concepts that emerge in each interview are compared with the previous ones, was used to confirm, challenge, clarify, develop and modify the concepts generated previously and to open up previously unidentified areas of enquiry (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin 1994). This allowed the generation of more focused questions, which were incorporated into subsequent interview guides and which enabled the analysis to move towards the development of more abstract theoretical categories (Charmaz, 2006; Strauss & Corbin, 1994). For example, responses were analysed and compared and codes representing similar psychological and behavioural reactions to diagnosis including: *researching illness and treatments, reading blogs, etc.*, were compiled and synthesised into a more abstract category labelled “*seeking information*”. Categories were then explored and refined through theoretical sampling.

The final step of the analysis involved identifying a core category/phenomenon which described the participant’s experience of chronic illness and which was related to and described the relationship between the other categories.

Results

The core concept identified in the data described the experience of chronic illness as progressing towards a *new normal*. This core concept was related to three interrelated
higher-order categories which were labelled “new body”, “new life”, and “seeking information”. The core concept and the higher-order categories are described below.

**A new normal**

Progressing towards a *new normal* involves adjusting to a changed body which may no longer look or be able to perform as it used to and which requires a new type of care. It also entails learning to live a different type of life involving: interruptions, health becoming a central focus, adjusting to having one’s choices restricted, having one’s future plans affected and living with an uncertain future. Additionally, it involves a process of information seeking which is continuous, helps the individual to manage the experience in multiple ways and has positive and negative psychological effects. Changes in any category influence the other categories and the experience of *new normal*.

![Figure 1. A Grounded Theory of the experiences of people who were diagnosed with chronic illnesses when they were young.](image)

For the participants, adjusting to a *new normal* represented a process which was continuous and iterative because it was influenced by the progressive nature of the illness, the participant’s personal development, the acquisition of knowledge and changing circumstances. Therefore, experiencing a chronic or progressive illness involved a constant revision of what is considered ‘new’ and ‘normal’, with implications for how the illness is responded to.
Participants described how the overall experience of illness varied over time and therefore, rather than representing a static, final stage in the process of adapting to living with a chronic illness, adjusting to a *new normal* represented adjusting to living in a state of process and constant change rather than arriving at a final level of adjustment:

"Everything is so dynamic and changing. It's never one absolute experience that happens to you at one point and that's it... it changes as you change, and as your life changes..." (Fiona).

However, other participants viewed *new normal* as an attainable state which they aspired to. It represented a state where their illness would stop progressing or where they would have come to terms with the changes they had already undergone and their current state of health. In this light, *new normal* represented a more static state that could be reached and adapted to and that therefore gained a sense of normalcy over time. For instance, Anne described coming to terms with the loss of function in her hands and with the idea that they would not fully recover or "go back to quite the same normal", and how their current level of function was now the 'new normal' for her:

"For me... I guess the new normal is... I'm hoping... well... as much as I'd love to get full use of my hands back, I don't know if that will be..., I don't know how much damage has actually already been done... whereas they might be a little bit better, but may not be exactly the way they were...".

1. New body

This category describes the participants' experience of adapting to the changes in their bodies and how these impact on their daily lives. The process primarily involves adapting to changes in the body's appearance, new limitations and requirements.

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3 Ellipsis points … indicate a pause in speech. Brackets […] indicate that material has been omitted.
1.1 Appearance. Participants with visible symptoms struggled to become reconciled with significant changes to their bodies including the disfigurement and impaired function of different body parts. Moreover, some participants required the use of devices that made their illness evident, such as oxygen contractors or wheelchairs. These changes to their appearance were experienced as breaches of privacy and constant reminders of their illness:

“They obviously will see a difference in the way I look from when they knew me before and when they know me now, so they do know something is up” (Anne).

Furthermore, they threatened their identity and self-esteem, and how they were perceived and responded to by others:

“I remember going into college and being like... you know... I had to use my wheelchair, and people just being like... treating me like awkward, you know... or like I was different and they felt sorry for me” (Becky).

Whether the participants’ bodies had undergone visible changes or not impacted differentially on their experience of illness. Those who had not changed visibly, and whose illness was therefore not ‘apparent’, described how this affected their credibility as an ‘ill person’, their need to explain and justify their symptoms and others’ reactions and expectations of them:

“They always say: “This disease, you know, you look healthy, you look fine” and “how could you be so sick”, or things like that, so, or: “You don’t look sick” (Anne).

Additionally, not having an apparent illness sometimes produced self-doubt and ambiguity regarding the validity of their experience, leading participants to question whether what they were experiencing was real:
"It got to the point that everybody thought I was a hypochondriac... and it got to the point that I thought I was going crazy because I had all these weird symptoms [...]" (Grace).

Participants described the role of doctors and others in legitimising their experience and elevating their status from that of ‘crazy’ or ‘lazy’ to ‘ill’ by providing a diagnosis:

"Finally someone was confirming what I had known for a long time... that I wasn’t crazy you know... I wasn’t a hypochondriac and there was something really wrong with me...") (Grace).

1.2 Abilities. The effects of illness on the participants’ bodies imposed new restrictions on their physical abilities and choices. Anatomical and functional changes and symptoms such as pain and fatigue directly impinged on the range and duration of activities participants could engage in, from basic activities like eating and breathing, to hobbies, work and plans for the future. Additionally, limitations on their physical abilities affected their interpersonal relationships. For instance, by increasing dependency or affecting their ability to maintain sexual relationships. The discordance between what participants wanted to do and what they were able to do generated feelings of loss, frustration, and depression:

"I can’t enjoy certain things... like my husband likes to hike, I can’t go hiking with him... I can’t stand for very long periods of time and walk very far, so I can’t enjoy... I used to love to go to the zoo and go to a museum park... just go out places... shopping... that’s even difficult..." (Anne).

1.3 Requirements. Progressing towards a new normal involved adjusting to their emerging and changing physical needs as their illnesses progressed and learning to manage them. The new physical needs were typically related to symptom reduction or management and required considerable and consistent care. For instance, participants
spoke of treatments, medication, and resting as becoming “normal” parts of their lives:

“You need to do your (physiotherapy) exercises and you need to take care of yourself and take your medication and do everything like that” (Grace).

In some cases, changes to their living and work environments were also required, to accommodate their changing needs and maintain as much independence and functionality as possible (e.g. access for mobility scooters). Although these adaptations were considered important to managing the illness, there was a sense that the special care required was often experienced as burdensome and restrictive (e.g. Bianca described it as a form of slavery: “I’m a slave to my body now, really”).

2. New Life

Experiencing chronic illness required participants to manage the transformations that illness caused in their lives. This category describes these changes, which primarily entail the interruption of life as known, the present becoming health-focused, having less choices, the disruption of future plans and a preoccupation with an uncertain future.

2.1 Life interrupted. Illness is experienced as an interruption of the participant’s life and it involves the reduction or loss of things that were important, or that the participants would have liked to experience, including independence, relationships, and careers:

“I had to quit my job... I had to pretty much quit my life, or the lifestyle that I used to have... I was living in Paris, I was a dancer... that’s what I wanted to do... that was my passion and everything. It’s a lifestyle that you can’t have if you’re ill” (Grace).
Additionally, as the onset of illness occurred when the participants were young, there was a sense that it had prevented them from experiencing different life stages in a more ‘usual’ way. Missing out on formative experiences (e.g. going out with friends) was felt to distinguish them from healthy people of their age and to have shaped their lifestyle and their development as a person:

"Another teenager might have just been able to go out and do something and not think about it... whereas I had to think about how I'm gonna rest... and how I'm gonna do it... and how I'm gonna feel afterwards... and all those kinds of things [...] that makes you grow up... but then at the same time... I missed out on a lot of like... the kind of coming of age experience which a lot of other teenagers have" (Becky).

2.2 Health-focused. Prior to becoming ill, participants had not been very concerned about their health, whereas this had now become a central concern in their lives. A large proportion of their time and energy was spent focusing on alleviating symptoms, resting, seeing doctors and following treatment. Additionally, overexerting themselves or feeling stressed exacerbated their symptoms and therefore resting, pacing themselves, and establishing new boundaries had become necessary parts of their lives. Having limited amounts of strength and energy required them to plan their days and make decisions regarding when and how much to work, rest, or socialise, in ways that weren’t necessary before becoming ill:

"In our case, we need to plan out our days. We know we have a specific level of energy and pain that we have to deal with and so we are not going to be able to waste any of that energy because once that energy is gone, that's it [...] So I have to make sure that I - I prioritise, you know? Like I say ok...What do I need to do today? [...] I have to make sure that I have enough energy to do all that. I'm not going to waste my time doing this or the other because I won't have enough energy to do what I really need to do [...]. We need to be specific in our
choices... you know? ...like, we don't have the luxury of not thinking about our choices” (Grace).

Participants described how their experience of illness and loss had taught them not to take their wellbeing for granted. Additionally, notions of health and illness had become relative. Participants described being mindful that their health might continue to deteriorate. Therefore, the quality of their present health is evaluated not just in light of their past but also their future health. In this way, while the present self is experienced as ill when compared with a healthier past, a threatening future can make the present health condition relatively more appealing and valuable:

"You don't realise how important your lungs are until you don't have lungs, and now I have to carry my life with an oxygen tank... and when before I could dance all night, now I can only dance for one song and then I have to rest... and not just that..., but... just thinking that there is a possibility that I might need a transplant... and my body might not be able to take it... or they might tell me that I can't make the list or anything... so I just... because of things like that, I try to make sure not to take my life for granted” (Grace).

However, although health had become a focus, most participants emphasised the importance of trying to maintain balance in their lives so that they were not completely taken over by their illness.

2.3 Diminished choices. Participants described how there were aspects of their illness, treatment and experience which they felt they had no control over. Therefore, their illness was experienced as disempowering and restrictive of their life choices and opportunities:

"Sometimes I feel really depressed about it, because I realise that I physically can't do something that I wanted to do, that I have to cancel plans, that I have
to — I can’t do certain things that I would love to do because it’s a lot of physical activity” (Fiona).

“This disease has totally change my life […] it has sort of taken away some things from me that I like to do, taken away advantages that I used to have” (Anne).

Moreover, as their illnesses are currently incurable and there are no tailored treatments available, participants often felt powerless and at a disadvantage to prevent the deterioration of their health:

“I have to keep telling myself there’s not much I can do about it. You know, I have to live with it. It sucks. It really does, but what else can I do? I don’t have a choice” (Anne).

The relative lack of awareness, funding, research and treatments available, compared with better-known illnesses, was also seen as an externally imposed limitation on their social standing and their choices of treatment and hope of recovery:

“All the money is going to larger diseases and all the research is going there […] no offence to the cancer people, but they’ve done enough research… they’ve got a lot of treatments, you know?…maybe it’s our turn. Shift the money our way! We need some more help… I really don’t like the fact that I’m limited to the medications I can take and even those medications might not have been tested so much” (Anne).

Conversely, there were aspects of their experience which participants felt that they could still influence, which was empowering and helped to enhance their quality of life and sense of control. For instance, participants felt that they could make choices to improve/manage their symptoms, wellbeing and prognosis by choosing to: take their medication, do physical therapy, change their lifestyles (e.g. changing their diets,
taking supplements, exercising), and complementing their treatment (e.g. alternative medicine, acupuncture). Participants emphasised the importance of acknowledging their conditions but also being proactive and taking charge of their health, focusing on what could potentially be changed, improved or prevented:

"I can keep it in check if I pay attention to it [...] if I'm diligent with my part of the work which is taking – exercising, being careful with what I eat, and taking stuff like Omega-3, MSM for your joints [...] I take tons of stuff" (Bianca).

2.4 Impact on future plans. Participants described how their illness affected important aspects of their future lives, identities and sense of purpose, including what careers they could pursue and where they could live or travel. Furthermore, participants described how the issues they had to cope with changed as they progressed through different life stages and how having an illness meant they had to navigate those things differently. For instance, deciding whether or not they could manage going to university, living alone, or having children:

"So things that will come up just because it's their time to come up during the process of a lifetime... well I have to deal with them a different way because I have ME" (Fiona).

Furthermore, in some cases, future plans have to be altered because of the illness. For instance, a participant described how, as she aged and her health deteriorated, she was faced with the possibility of potentially not being able to have children and even if she could, of having to plan ahead in order (if all went well) to keep her options open:

"Since I'm thirty one and I haven't had children yet, they advised me to get my ovules... um... my eggs taken out and frozen so they wouldn't be harmed by the chemo... but she [doctor] said...there is a possibility that the disease has affected your reproductive system and you might never produce them" (Grace).
2.5 Living with uncertainty. Participants described the unpredictability of their future becoming more salient after they were diagnosed. Uncertainty was primarily illness related and revolved around not knowing: when flares would occur, how symptom type and severity would vary over time, the speed and extent of illness progression, or whether they would go into remission or a cure would be found. Facing future health complications, increasing dependence and disability, or a premature death, had become common concerns. Additionally, the threat of unexpected changes in their experience of illness seemed to generate anxiety and to make it difficult to make short-term and long-term plans, as participants were unsure whether, when and in what ways their health might deteriorate further:

“I don’t really plan because, you know, the doctors told me I may not have been here. They didn’t expect me to live this long” (Lynda).

“It’s just scary the possibility of... because the doctor told me... if you don’t take medicine you can end up in a wheelchair... so I freaked out” (Bianca).

3. Seeking information

This category describes part of the progression towards a new normal, involving the accrual of knowledge of the illness and its prognosis, researching the best treatment options and learning how to manage the illness by seeking information from professionals and other people’s experiences, shared on the Internet. It is characterised by being a continuous process, serving multiple purposes, and having positive and negative repercussions.

3.1 Continuous process. Prior to and immediately following diagnosis, participants lacked information and understanding regarding their symptoms, diagnosis and prognosis. This phase was characterised by relying on medical professionals for information and by confusion, anxiety and uncertainty regarding the potential implications of their diagnoses. Information seeking served as a strategy to try to
understand their illness. However, information seeking continued throughout the illness, reliance on medical information diminished and additional sources were consulted as a way of coping with the issues that arose as illnesses progressed, circumstances changed and participants moved through different life-stages:

"An article from 2005 may not be good information in 2012 [...] They do more research, every day they're posting new stuff and these people in my chat groups and stuff, they're finding information on Scleroderma and related diseases and new findings like that, so there's a lot of new information coming out" (Anne).

3.2 Multiple purposes. Participants seek information that will help them to promote health, prevent deterioration and deal more effectively with their illness. Furthermore, knowledge about their illness and attempting new treatments and lifestyle changes based on acquired information provides a sense of control and fosters a sense of hope that these will yield positive results:

"I know I'm going to get better because I take really good care of myself and I exercise, I do yoga, I'm eating right. So I'm going to fight this disease as much as I can [...] whatever is in my court to do I'm going to do it so that I'm ok" (Bianca).

Hope of improvement helps participants to make sacrifices for their health and to endure painful and difficult challenges and treatments:

"The medications I'm taking aren't working... so I'm still trying to find something that will help... I start a new... hopefully start a new treatment on Friday... it's chemo so I'm not looking forward to that... but I'm hoping it will, you know... do its job..." (Anne).
Seeking information is also a means of establishing contact and building relationships with other ill people, creating a sense of identity, purpose and support:

"In finding these blogs... these people had shared their experiences... and I'm going... wait a minute... that sounds exactly like me... so... I kind of was able to meet people and question them on their symptoms, and things that they did, and what their doctors said" (Anne).

Furthermore, although the illness might not improve, having information on how to cope with it and what options are available can improve the overall experience by providing a sense of control and empowerment:

"While it's getting worse, and the symptoms aren't getting any better, my knowledge base is getting better on how to deal with certain things... or maybe that there's more options that I didn't know about before..." (Anne).

3.3 Double-edged sword. Participants described how finding information has both positive and negative psychological effects. Having information allows participants to take better care of themselves and provides them with a sense of agency:

"You may have to have a second opinion, or a third opinion but please, please, do not be passive about your health, especially with Lupus [...] you need to educate yourself and the doctors and be proactive. You have to be" (Lynda).

Additionally, seeking information from others' experiences can help to reduce isolation and provide a sense of community and social support:

"I've been part of this Multiple Sclerosis chat group...[...] for a couple of years now where...it's a group where we just go and help each other out... and give support and pray and vent and give information and stuff..." (Grace).
Shifting from an initial dependence upon doctors for information about their illness, towards becoming increasingly knowledgeable, results in the development of expertise on their condition, reduced helplessness and the ability to help and guide others:

"I can give them tips on the doctors themselves... the whole process of what the doctor's going to do, because I've been through it" (Anne).

Additionally, seeking information is a means to try to anticipate the future and thus relieve uncertainty and anxiety. In some cases, online patients are more accessible and have first-hand knowledge which is more useful and reliable than that of medical professionals. For example, when speaking about possible side-effects of a new treatment, a participant described the advantages of seeking information from people online:

"I can ask them... What was your experience with it?... Did you lose your hair?... Did you get sick?" (Anne).

Furthermore, information can provide hope and encouragement that circumstances will improve. Some participants looked for cases where people’s symptoms had improved or the illness had gone into remission:

"It is kind of really good... because it gives people hope" (Becky).

Illness-related information can also be used by participants to compare themselves to other people with the same or different illnesses. This form of social comparison can sometimes make participants feel better about their situation:

"ME is like winning the lottery if you are going to have one of those diseases... in that sense I don't complain at all and feel really grateful and so aware of what
other illnesses are like and how horrible it must be to have a more serious illness” (Fiona).

Nevertheless, seeking information is also at times a negative experience. Participants described feeling terrified and depressed when realising the chronicity and/or degenerative nature of their illness and when coming across information and accounts that they feared could be representative of their own future:

“It's been a little scary in a way... because a lot of these people are so bad off... and I'm afraid... is that the direction I'm going in? ... Is that what's going to happen to me?” (Anne).

Discussion

The aim of this study was to contribute towards the process of developing a theory about living with chronic illness when diagnosed at a young age by exploring the subjective experiences of people diagnosed with chronic illnesses when they were young. For this purpose, a GT methodology was adopted. The core category and the subcategories elucidate their experience and describe a progression towards a new normal, which involves adapting to a new body and a new life and seeking information. The process of adapting to a new normal and the insights gleaned from the participants’ accounts are discussed below.

Adapting to a changing body and experiencing body image dissatisfaction with certain illnesses formed part of the process of adapting to chronic illness and progressing towards a new normal. This supports previous research with adults (Benrud-Larson et al., 2003; Charmaz, 1995), adolescents (Larouche & Chin-Peuckert, 2006) and children (Schmitke & Schlomann, 2002) and suggests that therapeutic work addressing the psychological and embodied experience of adapting to changes in people’s appearance, abilities and requirements could contribute to the psychological
and physical health of clients who are diagnosed with a chronic illness when they are young.

Adapting to a new life formed part of the process of progressing towards a new normal. Participants described their lives being disrupted and restricted by illness and facing uncertain futures. These experiences impact on people’s self-concept, identity and self-continuity (Charmaz, 1983; Iyer et al., 2008). It could be argued that some participants adjusted or were adjusting to changes to their identity and self-concept by identifying with others with the same illness through developing new in-groups (e.g. “we don’t have the luxury of not planning our days”) and perceiving healthy people, or those with other illnesses as out-groups (e.g. “cancer people”). From a social identity theory perspective (Tjafel & Turner, 1979), participants had categorised others and themselves on the basis of health or illness and type of illness and were now comparing themselves with others and competing for resources (e.g. research funding). Participants identified with different groups and developed a sense of identity, which was facilitated by the process of seeking information and relating to others with their illness. Iyer et al. (2008) argue that taking on a new group membership is key in restoring or maintaining a person’s sense of self-continuity. Information seeking and relating with others can serve as a means of preserving self-continuity and developing a sense of purpose and belonging, thereby coping with isolation and discrimination. Additionally, for some participants, it had become a way of grouping forces to try to generate social change by increasing awareness about their illness.

Furthermore, participants in this study struggled to adapt to diminishing choices and control in their lives. However, an important part of the participants’ experience involved seeking ways to keep their options open or discover new ways of exercising choices. Part of their new normal involved preserving, identifying and generating areas of choice. This may be in order to preserve one’s control, freedom and self-image. Indeed, allowing adolescents some autonomy in the management of their conditions is important (Burns et al., 2006). Similarly, Charmaz (1983) found that
exercising choices helped housebound adults with chronic illness to feel less restricted, preserve their self-image and reduce suffering. Participants in the present study also expressed how exercising choices, when possible, improved their experience of illness and wellbeing. This provides insight for therapeutic interventions, as helping clients to identify and generate areas of choice is not only developmentally crucial but can be empowering, produce a sense of purpose and meaning, improve self-esteem and help young people to preserve or ‘re’-construct a positive validated self.

Participants described how their experience of chronic illness changed as they progressed through different life stages, which is in line with research suggesting that age and life stages impact upon the types of problems and consequences that people with chronic illness deal with (Lubkin & Larsen, 2006). Additionally, participants expressed anxiety regarding ageing with an illness. In terms of the impact of illness on their development and future plans, therapeutic interventions could help clients to anticipate changes or difficulties, develop new coping and self-care strategies, process loss, maintain a sense of purpose and find ways of maximising their wellbeing through transitions and decisions.

Participants' lives had become health-focused as part of their *new normal*, but they emphasised trying to maintain a balance in order that their whole experience and identity didn’t revolve around illness. This has been described as one of the paradoxes that adults living with chronic illness experience, whereby in order to live a life that is not illness-focused, health management and planning must become central, so that truly valued activities can be engaged in (Paterson, 2001). Helping people to plan and prioritise could help them to live more enriching lives in ways which don’t necessarily involve forsaking valued and meaningful activities or their health. Additionally, helping people to shift their focus between their illness and other aspects of their lives, (Paterson, 2001) according to their changing health needs, could help buffer against feeling dominated by illness and against one’s multiple identities being overshadowed by the identity as a ‘sick person’.
Participants sought information in order to understand their illness and stay abreast of illness-related research and treatments, with the hope of managing their illness effectively, influencing prognosis and maintaining a sense of control. As such, hope represented a driving force for their behaviour and an emotional buffer. Over time, participants developed competency in the arena of their illness and thus became increasingly powerful and knowledgeable. Åsbring and Närvänén (2004) found that women with uncertain illness trajectories sought information as a means to maintain a sense of control over their health. Whereas their participants sought information primarily in order to influence their health care providers, participants in the present study sought information as a strategy by which to control their health, maintain hope, reduce uncertainty and make sense of their experience. Additionally, it helped them to relate to others and develop a sense of identity. Indeed adolescents are primarily drawn to the social and informational aspects of the internet (Hellenga, 2002) and adolescents with chronic illnesses have been found to access computer-mediated support groups primarily in search of informational, emotional and social support (Elwell, Grogan & Coulson, 2011). Moreover, Iyer et al. (2008) emphasise that engaging in meaning-making helps groups to reduce uncertainty and to orientate themselves in social contexts with regard to other groups and systems. They argue that belonging to a group provides a perspective from which to understand the world, which provides a sense of security and increases wellbeing in times of transition and identity adjustment. Indeed, an important aspect of participants’ experience of progressing towards a new normal involved using the exchange of information to establish relationships with others, which served as a source of support and identity.

Limitations

The findings from this study are based on the experiences of volunteers who were interested in sharing their experiences of chronic illness and helping to advance research. In addition, the participants in this study had the resources and skills to access information and social support through the use of technology. Therefore, these findings pertain only to young people in similar circumstances. Furthermore, although
the study's aim was to explore the experiences of people who had been diagnosed when they were young, some of the participants were diagnosed in their early twenties. This dilutes the validity of the findings, since, although there is some overlap in how individuals across different ages may experience illness, there are particular developmental challenges and resources which adolescents with chronic conditions must grapple with, which differ from those faced by young adults and other age groups. Glaser and Strauss (1967) argue that in order to develop a substantive theory which faithfully represents the experiences of one substantive group, a narrow sample is required. Therefore, including in this study the experiences of non-adolescents may have obscured important differences and similarities between the experiences of adolescents and young adults with chronic conditions, thereby rendering the emergent theory less nuanced, generalizable, and representative (Cutcliffe, 2000) of young people's experiences. Selecting a narrower sample in future could prevent this issue.

In terms of methodological limitations, there is disagreement amongst grounded theorists about what constitutes the best type of data for this methodology (Morse, 2001). For instance, Glaser (1992) advocated the use of observational and interview data in order to uncover participants' meanings, whereas Morse (2001) argues that observational data only offers "snapshots" of a process, rather than the continuous overview provided by unstructured retrospective interviews which is necessary in order to develop a theory. However, Benoliel (1996) warns that relying exclusively on interview data can undermine the purpose and outcome of grounded theory studies, as it can result in an emphasis on participants' internal experiences rather than their social contexts, structures and processes. In order to address this issue, future research could draw from several data sources in order to obtain a broader and fuller perspective. Indeed, Schreiber (2001) argues that this would enable the researcher to "develop explanations for the variation in the data and to unify them at a more abstract level into a [good grounded] theory" (p.64).
This study aimed for theoretical sufficiency rather than saturation. McCann and Clark (2003) warn that, since theoretical saturation is one of the key aspects of GT methodology, a premature closure in data analysis will result in a descriptive rather than abstract theory which will lack conceptual depth. Preceding the search for participants with a focus group would facilitate a clearer idea of whom to include in theoretical sampling (i.e. who could contribute the most useful/relevant data?), thus enabling the initial data to be gathered in a more focused way. This could help to streamline the research process and allow more time for a greater level of saturation and abstraction to be reached within a limited time frame. Additionally, Morse (2001) warns that maintaining the study grounded in participants’ accounts limits the level of abstraction which can be reached and that a certain level of decontextualisation is required in order to “raise the level of abstraction of a theory by moving it to higher level concepts” and to increase the level of generalizability of the theory (p. 9). However, Thomas and James (2006) warn that in its axial coding, categories and subcategories, grounded theory “relegates the original voice - the narrative - of both the respondent and the discussant in the research exercise... it implies a dismissal of the direct validity and import of people's accounts” (p.790). Perhaps future research drawing on participant narratives, or combining GT with methodologies that closely follow participants’ accounts such as Narrative Analysis or IPA could add richness and context to the more conceptually abstract GT, thereby helping to balance between description and a theory, and between individual and social processes.

Finally, in order to fully understand the interplay of development and chronic illness, a longitudinal perspective is required. Kralik, Paterson and Coates (2010) denounce the lack of sophistication in chronic illness research, which has “so far largely neglected a lifespan developmental perspective” (p. 46), which could greatly enrich our understanding of how chronically ill people experience and manage their development. Indeed, a longitudinal exploration of the developmental and adjustment processes, significant experiences and lessons gleaned over time would shed an invaluable light on the development of theory pertaining to living with chronic illness from a young age.
Clinical Implications

Counselling psychology emphasises the inter and intra-subjectively created meanings, beliefs, context and processes which affect people’s psychological wellbeing (British Psychological Society, 2010). This study provides a rich description of the complex experience of chronic illness, which affects their identity, development and emotional, physical, cognitive and sexual wellbeing, as experienced by people who were diagnosed with chronic illnesses when they were young. These findings contribute towards a body of research which aims to develop theory with which to inform therapeutic work with this population. They highlight the importance of helping clients to: manage the changes to their bodies and life-styles; explore and maximise their options and develop management strategies, to improve their sense of empowerment and independence; help clients to deal with feelings of anxiety and depression about present limitations and an uncertain future; and improve their self-esteem and self-confidence. In cases where people’s bodily appearance and function have changed, therapeutic work explicitly addressing self-image and intimate/sexual relationships could be beneficial. Additionally, young people with chronic illness experience different challenges as they progress through different life stages and develop their sense of identity. Therefore, helping them to navigate life stages and integrate their different identities may help them to manage their experience in a more meaningful and balanced way. However, Parahoo (2009) warns that, developing a theory is only a first step, as in order to ascertain its value and relevance, it must then be implemented in practice, tested and evaluated. As such, the potential implications discussed remain tentative and are yet to be evaluated.

Lastly, promotion of mental health with this population cannot be limited to psychotherapeutic work. Owing to the complicated and developing nature of chronic illness, it seems important for mental health professionals to be informed of the health issues their clients might potentially face and to work closely with medical professionals to find the best ways of promoting their clients’ health and quality of life. Additionally, wellbeing is also affected by the social and political contexts that
young people with chronic illnesses live in. At a social and political level, participants had experienced difficulties in terms of finding or maintaining employment, dealing with discrimination and stigma and an insufficient public and scientific awareness of their illnesses, with implications for the resources and research devoted to supporting them. Therefore, advocacy for clients with chronic illnesses seems paramount to helping to improve their wellbeing.

Conclusions

This GT study contributes towards the development of a theory about the experiences of people who were diagnosed with chronic illnesses when they were young. The experience of chronic illness is an iterative and continuous process of adapting to a new normal. The study contributes towards a richer understanding of people’s experiences, provides new insights into how illness influences their identity and development and discusses the clinical implications of the findings.
Personal Reflections

“Study participants, like us, hold diverse meanings and live in multiple realities. Thus, like paintings, our portrayals of them and their worlds reflect certain, although not all, images of their lives” (Charmaz, 2002, p. 319).

My assumptions, before starting this research, were that: the experiences of people who were diagnosed with a chronic illness when they were young are different to those of young healthy people; the experiences of people who were diagnosed with a condition when they were young are different to those of older people with chronic illnesses; health-related experiences and perspectives change over time; and that being diagnosed early in life is a different experience to being diagnosed at an older age. I tried to be mindful of these when researching, as I did not want to impose my assumptions on the participants’ experiences. I enjoyed being challenged by participants’ stories and learning interesting things about their experiences that I had never heard of or thought of before. I also found the Grounded Theory approach quite containing as I felt that it helped to keep the analysis grounded in the data.

Charmaz (2002) reminds us that when telling a story, one is always faced with whether “to tell the story, a story, or not to tell?” (p.306), a comment which resonated with me throughout the research. I became acutely aware that the stories told by participants do not replicate experience and that they are constructed differently at different times for different audiences. This was especially interesting when considering my different roles as friend, researcher, or therapist. Indeed, it was interesting for me to reflect on what aspects of their experience participants decided to focus on or share and which to avoid or omit, whether consciously/ deliberately or not. In some cases, I knew the participants well, and I expected to obtain richer and fuller accounts of their experiences than from participants whom I did not know. This assumption was often challenged. Although some were willing to disclose highly personal information, others were not, even if they had shared it with me already in the past. In addition, participants whom I did not know did not seem less open or
willing to share difficult or intimate experiences than participants I knew well. In some cases they were willing to share even more, possibly because they did not know me. I was also aware that each account, though rich and detailed, could not fully describe the participant's experience. Indeed, as one participant highlighted:

"I just think it's something that I could write a book about... and in some ways when you have to talk about it in half an hour, maybe an hour, maybe in two hours, or even... if I have five minutes and it comes up, well I will try and explain what it is like in five minutes... now I have tried to explain what it is like in your time frame, but I could write a book about it too... think how much I go into detail and into many things that I haven't had time to... it's difficult, you could really talk about it from many, many, many different angles".

In every interview I struggled with the tension of whether or not to pursue questions or subjects that I felt were being avoided or minimized, especially with participants who I knew had more to say on certain subjects but were not doing so. I think that I managed to respect their accounts of their personal experiences and not influence their responses or force a narrative upon them. However, I often felt frustrated when I felt or knew that important information was being consciously/unconsciously withheld or that there was a disparity between their experience as I knew it and their account during the interview. On the other hand, this helped me to reflect on what was not being said and why and provided much food for thought about them and myself.

I was surprised by the emphasis most participants placed on coping strategies and staying positive. Some had really embraced the role of guiding others in their experience of illness and sharing what they had learned. I had expected to hear more despair and hopelessness in their accounts. Instead I felt humbled by their courage, resilience and adaptability. I was also surprised by the importance of doctors and others in validating their experiences, even those symptoms which I would think would be more concrete and 'real' like physical pain. Yet without validation from others, even that aspect of their experience was questionable. I had underestimated the
power of external confirmation of subjective experience to make it valid and make sense of it. This made me more sensitive to the stigma and struggle of clients with mental health issues which are very real but not visible.

A further difficulty I encountered involved managing the tension between my roles as a friend, a researcher and a practitioner, especially as participants talked about difficult and upsetting experiences which I would normally respond to differently from within my different roles. I was often left feeling slightly conflicted, guilty and even incompetent as I evaluated myself from the different positions. Although often uncomfortable, this was a valuable experience in terms of learning to manage and negotiate my different roles and identity.

Finally, the emphasis participants placed on resting and taking care of oneself with enough sleep, vitamins, good diet and boundaries really affected me. I have always been health conscious, but I suddenly found myself at the shop buying all sorts of supplements and taking regular exercise and breaks. I think I myself was scared by the participants' accounts and the prospect of a lifelong illness. I feel I have learned from their experiences not to take little things for granted and that my health and enjoying my life and loved ones are the priority and this has been really essential at this point in my life, when I could so easily run myself into the ground. I am grateful to my participants for reminding me of what is important to me.
References


Schreiber and P. N. Stern (Eds.), *Using grounded theory in nursing* (pp. 1-16). New York: Springer.


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Journal of Pediatric Nursing, 13, 210-223.


12th January 2012

Dear Isabelle

Reference: 680-PSY-11 RS
Title of Project: Chronic illness and young people: A Grounded Theory Study

Thank you for your re-submission of the above proposal.

The Faculty of Arts and Human Sciences Ethics Committee has now given a favourable ethical opinion.

If there are any significant changes to your proposal which require further scrutiny, please contact the Faculty Ethics Committee before proceeding with your Project.

Yours sincerely

[Signature]

Dr Adrian Coyle
Chair
Chair's Action

Ref: 680-PSY-11 RS
Name of Student: ISABELLE CROSSLEY
Title of Project: Chronic Illness and young people: A Grounded Theory Study
Supervisor: DR DORA BROWN
Date of submission: 29TH NOVEMBER 2011
Date of re-submission: 10TH JANUARY 2012

The above Project has been re-submitted to the FAHS Ethics Committee.

A favourable ethical opinion has now been given.

Signed: [Signature]
Dr. Adrian Boyle
Chair

Dated: 13TH JANUARY 2012
• I the undersigned voluntarily agree to take part in the study on the experiences of people who were diagnosed with a chronic illness when they were young.

• I have read and understood the information sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my health and well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

• I agree to inform the investigator immediately if I suffer any deterioration of any kind in my health or well-being.

• I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the results of the study on the understanding that my anonymity is preserved.

• I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.

• I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

• Please tick here if you do not wish to be contacted for a follow-up interview □

Name of volunteer (BLOCK CAPITALS) ....................................

Signed............................................................................................................................

Date.................................................................................................................................

In the presence of (BLOCK CAPITALS) .........................................................

Signed............................................................................................................................

Date.................................................................................................................................

Name of researcher/ person taking consent (BLOCK CAPITALS) ........................

Signed............................................................................................................................

Date.................................................................................................................................

Participant Number (you will need this if you want to withdraw your results at a later date): ___
Postgraduate Research Study: **What are the experiences of people who were diagnosed with a chronic illness when they were young?**

This information sheet will provide you with information explaining the purpose of the research and why you have been invited to participate in this study. Below you will also find information regarding what your participation in the study will involve and contact information in case you have any questions or would like more information. Please take time to read the following information carefully and to decide whether or not you wish to take part in the study. Thank you for reading this.

**What is the purpose of the study?**

The aim of this study is to explore the experiences of people who were diagnosed with a chronic illness when they were young in order to broaden and improve our understanding of what it is like for young people to live with chronic illness. A better understanding of chronic illness from the perspective of people who were diagnosed with a chronic illness when they were young could help provide fresh and richer understandings their experiences. This could help to develop new ways of understanding and dealing with illness and inform the psychological treatment of illness in young people.

**Why have I been chosen?**

You have been invited to participate in this study because your experiences, thoughts, and feelings can offer a unique and personal perspective on what it is like to live with an illness.

**What will participation involve?**

The interview can be carried out at a location which is convenient and comfortable for you. The interview will be based around a semi-structured interview which will take approximately 40-50 minutes. If you would be willing, a follow-up interview to clarify or expand on certain points would be carried out at your convenience before April 2012.
This interview is intended as an opportunity for you to describe your experiences as a young person with a chronic illness. The interview will be recorded, transcribed into text form, and stored digitally. The transcription may be carried out by the researcher or a transcription service bound by a confidentiality agreement. In order to ensure confidentiality, the information will be securely stored on a password protected computer, and your name and any other identifying information will be removed so that you cannot be recognised by the information provided. Any forms containing personal information will be stored in a locked unit which only the research supervisor will have access to. As part of the presentation of results, your own words may be quoted. However, this will be anonymised, so that you cannot be identified from what you said. In line with the Code of Good Research Practice (http://www2.surrey.ac.uk/fahs/staffandstudents/ethicalprocedures/briefing/ethics_documents_list.htm), all the data will be securely stored for a period of time and will then be destroyed.

Please note that your participation is voluntary, and you can decide not to answer questions that you don’t wish to, and to stop the interview at any point. You can also decide to withdraw from the study in which case the information you provided will be removed and destroyed.

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Additionally you will be provided with the interview questions before the interview takes place so that you will have an idea of what to expect. Should you wish to, once the study is complete a copy of the study could be provided for you.

This study has been given a favourable opinion by the Faculty of Arts and Human Sciences Ethics Committee of the Faculty of Arts and Human Sciences at the University of Surrey.

You can contact the University of Surrey using the details below for further advice and information:

**Supervisor’s name:** Dr. Dora Brown

**Department address:**
Department of Psychology
Faculty of Arts and Human Sciences
AD Building
University of Surrey
Guildford

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Thank you for participating in this study!
Participant Debrief Form: **What are the experiences of people who were diagnosed with a chronic illness when they were young?**

Participant Number (you will need this if you want to withdraw from the study at a later date): ___

The general aim of this study is to explore the experiences of people who were diagnosed with a chronic illness when they were young, so as to shed light on the meanings, processes, conceptualisations of illness, and lived experiences of illness from the perspective of people who have experienced illness from a young age.

The objectives of the research are: firstly, to develop theory and provide fresh understandings in the field of chronic illnesses; secondly, to provide counselling psychologists and psychotherapists with a richer understanding of the experiences of people who were diagnosed with a chronic illness when they were young; and thirdly, to add to counselling and psychotherapeutic literature with new ways of understanding people's experiences of chronic illness within the psychological treatment of illness.

People who were diagnosed with a range of chronic illnesses when they were young have been invited to participate in this study and have been asked to describe their experiences, thoughts, and feelings, and personal perspective on what it is like to live with an illness.

If you would like further advice and information please contact the University of Surrey using the contact details below:

**Supervisor's name:** Dr. Dora Brown

**Department address:** Department of Psychology, Faculty of Arts and Human Sciences, AD Building, University of Surrey, Guildford, Surrey, GU2 7XH, UK

**Email:** dora.brown@surrey.ac.uk

**Phone:** 01483 68 3979

**Researcher:** Isabelle Crossley

**Department address:** Department of Psychology, Faculty of Arts and Human Sciences, AD Building, University of Surrey, Guildford, Surrey, GU2 7XH, UK

**Email:** ic00027@surrey.ac.uk

**Phone:** 01483 68 3979
In addition, if you feel distressed or concerned after discussing your experiences living with chronic illness and feel that you would benefit from some additional support or information, you may wish to contact some of the sources listed below:

**The British Psychological Society**  
Address: St Andrews House, 48 Princess Road East, Leicester, LE1 7DR  
Tel: +44 (0)116 254 9568  
Fax: +44 (0)116 227 1314  
Email: enquiries@bps.org.uk  
Web: www.bps.org.uk

**UK Council for Psychotherapy**  
Address: UKCP, 2nd Floor, Edward House, 2 Wakley Street, London, EC1V 7LT  
Tel: 020 7014 9955  
Fax: 020 7014 9977  
Email: info@ukcp.org.uk  
Web: www.psychotherapy.org.uk

**Scleroderma Society**  
Address: The Scleroderma Society, PO BOX 581, Chichester, PO19 9EW  
Tel: 020 7000 1925  
Email: info@sclerodermasociety.co.uk  
Web: www.sclerodermasociety.co.uk

**ME Association/ ME Society**  
Address: ME Association Head Office, 7 Apollo Office Court, Radcliffe Road, Gawcott  
Bucks, MK18 4DF  
Tel: 01280 818964  
ME Connect helpline: 0844 576 5326  
Email: meconnect@meassociation.org.uk  
Web: http://www.meassociation.org.uk/

**UK Fibromyalgia**  
7 Ashbourne Road, Bournemouth, Dorset, BH5 2JS  
Tel & Fax: 01202 259155  
Email: info@ukfibromyalgia.com  
Web: www.ukfibromyalgia.com

Thank you for participating in this study!
Age: _______
Gender (please circle): Male / Female
Ethnicity: _______
What is your diagnosis?: _______
At what age were you diagnosed?: _______
What is your marital status? (please circle): Single / Married / Separated / Divorced / Widowed / Civil partnership / Other (please specify) _______
What is your living arrangement? (please circle): Live alone / Live with spouse / Live with partner / Live with family / Live with friends / Assisted living / Other (please specify) _______
What is your education level? (please circle): Less than secondary school / Secondary school / at University / University graduate / Postgraduate student / Postgraduate / Other (please specify) _______
What is your employment status? (please circle): Full-time / Part-time / Self-employed / Unemployed with benefits / Unemployed without benefits / Other (please specify) _______
APPENDIX F - SAMPLE INITIAL INTERVIEW SCHEDULE

1. To start with, would you mind talking about X and what you think X is?

2. Would you mind letting me know what your experience of X has been like up till now?

3. How do you deal with X now?

4. What does it mean for you to have experienced X?

5. How do you see yourself in the immediate/long term future?

6. Is there anything else you would like to add to what you have already said?

4 Interview schedules will be adapted according to participants' specific illnesses (e.g. Scleroderma, Fibromyalgia, etc.)
1. To start with, would you mind talking about X and what you think X is?

2. Would you mind letting me know what your experience of X has been like up till now?

3. How do you deal with X now?

4. Do you feel there has been any change in how you deal with X?

5. What does it mean for you to have experienced X?

6. What was your experience like in terms of symptoms emerging, arriving at a diagnosis, and starting treatment?

7. What has your experience been in terms of using the Internet? Some people have found it helpful and others have not. What was it like for you?

8. What has your experience been like in terms of getting support?

9. How do you see yourself in the immediate/long term future?

10. Is there anything else that has been personally important in your experience or that you would like to add to what you have already said?

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5 Interview schedules will be adapted according to participants' specific illnesses (e.g. Scleroderma, Fibromyalgia, etc.)
INTERVIEW X – APRIL 2012

I: Ok, perfect! Ok, so to start with, would you mind talking about scleroderma and what that is for you?

P: Well, it’s this disease that has totally changed my life, and I’m not sure exactly for the better. It has sort of taken away some things from me that I like to do, taken away advantages that I used to have, you know? I’m young. My husband has recently retired from the military and I was looking forward to a new life, and unfortunately, I had to alter that a bit.

I: Right.

P: So.

I: Yeah. So?

P: Sorry. Go ahead.

I: No, no. Please, go ahead. I didn’t mean to interrupt.

P: Oh, no. That’s ok.

I: Yes, so it seems like it has taken things away and changed things. You said in ways that weren’t necessarily positive. Does that mean that you see anything as positive, or... because it seems overall that it’s been a negative experience.

P: Well, everybody I always hear says, you know, God does things, you know, He only does things that will... What is that saying? Will give you things that you can handle, but I would prefer not to handle these things. You know, it has affected my body in a very horrible way, I can no longer... I used to work the garden. That is more difficult now, if not impossible. I can’t, you know, bend in ways that I used to, like getting down on my hands and knees, so I can’t enjoy certain things, like my husband likes to hike. I can’t go hiking with him. I couldn’t even think about getting into a sleeping bag, let alone... or on the ground. I can’t stand for very long periods of time and walk very far, so I can’t enjoy... I used to like to go to the zoo and go to a museum park, just go out places, shopping... That’s even difficult. Lifting things, ‘cause I’ve lost a lot of strength, so everyday tasks: blow-drying my hair, brushing my teeth, things like that, because I can’t grip any more. I’ve lost full use of my hands. Luckily, I can still work. But, sleeping, I used to love to sleep, and even that’s more difficult now, ‘cause I can’t stay in the same position for a long period of time, otherwise I get very stiff and sore. Currently the medications I’m taking aren’t
working, so I’m still trying to find something that will help. I start a new… hopefully start a new treatment next Friday. It’s chemo, so I’m not looking forward to that but I’m hoping it will, you know, do its job and maybe things will let up a bit. So, like I said, things have not exactly been a lot of fun. You know, I’ve had to resort to, it’s like an old lady, you know.

I: Yeah. So it sounds like there’s been a lot of changes for you. I wonder… I guess you have kind of covered it. I guess… I wonder about what your experience has been up to now, whether you see it’s gone through stages, or in waves, or just how… ‘cause I know you have touched on and there’s been an adjustment to living in a different way and having to give up things that you like doing and…

P: I’m adjusting. I have friends that, you know, are very supportive, and my family and, you know, my husband helps me quite a bit, and I’ve found tools, we’ll say, that have kind of helped with picking things up. My knees are very bad and I live in a house that has very low toilets, so I had to order, like a riser, but it helps a lot, and it, you know? I found I go to physical therapy, and when I can’t go, I actually found online where I can purchase some of the same tools they use, so I can do it at home, and so I can get at it at my own pace, you know. Because I work full-time and then I’m constantly going to doctors’ appointments and things like that, it gets very wearing driving all over town, you know, and I don’t get home till late, so sometimes I like to cut back and maybe do some of these things at my own pace. And, you know, I’ve adapted in other ways. I have a lot of help. People at work understand, so they help me a bit too. I work in a place where I have use of very strong young men… (Laughs) So that when I can no longer load the paper and things like that, I just call up somebody, kind of put in my order for a few strong young men to lift boxes and stuff like that for me and, you know? So I’ve made adjustments.

I: Yes. And so how do you feel you deal with scleroderma now? Maybe, I wonder if there’s been any change from when you initially started feeling the symptoms till now, or…

P: It’s actually gotten progressively worse, so back then… but now I have more information. Back then, I was new to the disease, not that I’m not new now ‘cause I’ve only had it for less than two years, but I’ve met more people online who have shared their experiences, and done a lot more research. I’ve had to meet with more doctors, so you know, everybody is filling me in a little bit more, so while it’s getting worse and the symptoms aren’t getting any better, my knowledge base is getting better on how to deal with certain things or maybe that there’s more options that I didn’t know about before. So I’m learning more, and hoping that in the near future things will calm down and maybe make a turn for the better and that I will just have had this period of time when things were not so great (laughs) but getting better and we can just kind of chalk it up to: “Oh! I had those couple of bad years.”

I: Right.
P: Positive thinking.

I: Yes, so you’ve mentioned the internet a couple of times. I guess I’ve had different accounts of it. Some people saying that they found it really useful in some ways, others saying they’ve been recommended not to look on the internet for information. What’s your experience been?

P: When I first started, looking stuff up, if you googled it, there was a lot of very scary... All the medical websites were very scary information and even my doctor and a couple of accounts of blogs of people who had blogged their experience and said: “Yes. It’s very scary information” but in finding these blogs, these people had shared their experiences and I’d look at them and I’m going: “Wait a minute, that sounds exactly like me”. So I kind of was able to meet people and question them on their symptoms and things that they did and what their doctor said. I could find... and there’s new articles every day but a lot of information is old, because there’s not a lot of research, so some of the older articles might be a little scarier, because back then, things were a lot worse. For maybe certain medications, whereas now they may have perfected them over the years that they’ve learned from...Say for instance this one that I’m taking, or will be taking. Back when some of the articles came out, they were having incidences of bladder cancer and things like that and a lot higher and as I spoke to... I think it was a dermatologist who has a lot of experience with scleroderma, he was explaining things to me. He said: “Yes, but now, they’ve learned their lesson and they’ve learned to change things a bit as far as hydrating people, and you know, monitoring them better, so it’s not as bad as it used to be”. Things have gotten better over the years, so in that way, because the internet holds things for ever, you know, an article from 2005 may not be good information in 2012.

I: Right.

P: But also, as, you know, they do more research, every day they’re posting new stuff and these people in my chat group and stuff, they’re finding information on scleroderma and related diseases and new findings and things like that, so there’s a lot of new information coming out that’s very helpful. So, it’s kind of both. There are some very scary things out there and then there are some very helpful things and encouraging things.

I: And so in terms of chats and everything, what has that experience been like, for you?

P: It’s been a little scary in a way, because a lot of these people are so bad off, and I’m afraid: is that the direction I’m going in? Is that what’s going to happen to me? Is it a glimpse into my future? But then it’s been helpful because: 1/- they listen, you know, so you can kind of say things that you might not be able to say to other people, and are always very, you know, supportive; 2/- you can ask kind of embarrassing questions, because some people... somebody has probably already had an experience like that,
and they're always searching for new information or some of them have had experience with the same medications and they can tell you the symptoms they had with it. For instance, this one I'm going to be taking, there is people out there that have already taken it, and I can take from them... I can ask them: "What was your experience with it? Did you lose your hair? Did you get sick? My plan is to take it on a Friday to have the weekend to recover and go back to work and I can ask them: "Do you think that's feasible? Do you think it will work? What was your experience with it?" And you know, while everyone had a different experience I can tick off all those and see, and then there's two forms of it. Who took the pill form and who's taking the IV form? Which one is, you know, better? Things like that, so, you know... But a lot of these people also have multiple problems, or they were diagnosed so late that maybe their damage was so far gone that things won't help them now. I think that I was lucky that I was diagnosed early on, 'cause as soon as I noticed the first thing, I went straight to the doctor and we started working on stuff and it was relatively quickly, maybe a few months, before I had this diagnosis, but in the meantime, I was diagnosed with R.A. originally, and the medication my doctor gave me is one of the same things they use initially anyway, so either way it would have worked out.

I: Ok.

P: It turned out that my scleroderma symptoms started to show up a few months after that and so my doctor changed my diagnosis and I've been lucky I have so far assembled an excellent team of doctors who seem to be knowledgeable and communicate with each other and you know, do have my best interests at heart, so you know... Others are not so lucky, 'cause they live in areas where there's no access, where their doctors have never heard of this disease, have no experience so... advantages of living in a bigger city.

I: And so, I guess, some people have talked about their experience of the symptoms coming up and then arriving at a diagnosis and it seems, you know, as you were saying some people are diagnosed before others and it really changes the way that... how soon the treatment comes on, and how the person feels in the meantime, and I was wondering what your experience had been like in that sense?

P: Well for me, it was... it started with the swelling of my hands. And so I went to the doctor 'cause it just didn't seem right and he thought it might have been carpal tunnel because I'd also been having issues with my wrist and at my job I spend a lot of time on the computer, so he sent me to physical therapy and I noticed that not only was it not helping, they couldn't get the swelling to go down, but then it started to spread to things like my knees. You know, obviously, carpal tunnel does not spread to your knees, so I went back to the doctor and I said: "Well we need to figure out what's going on, and of course he immediately ordered a whole battery of tests and found out it was something autoimmune, so instantly he sent me to a rheumatologist who did more tests and, you know, that all happened within a matter of maybe a couple of months, and so it was relatively quickly, and so, from there, you know, the
rheumatologist not only ordered the battery of tests, but (distracted)??? (13:40) you know, I’ll need to go and get this done and that done, like I needed to go get an echo from my heart, just to make sure that everything was working properly, so I need to do a breathing test to make sure my lungs were functioning properly, because scleroderma affects your lungs, and with the discovery that at the time my lung capacity was not that great and I had pinky skin that showed slight damage, so, you know, all the initial tests starting to lead to: “Ok, now we’re going to do this treatment now we’re going to do this treatment”, so it all happened rather quickly, for me, anyway. And it was just sort of... It was like the snowball effect, you know, like the little Chinese snowball rolling down the hill and just got bigger and bigger, but the quicker I did it, the quicker I could get things taken care of or really try to slow it down or stop it before it got too bad.

I: Yeah. I wonder if this seems in terms of... like medically that it’s a good thing that it went quite quickly.

P: Yes.

I: I wonder if kind of emotionally or psychologically that might have been a bit hard in a way, just because of the speed of it. I wonder what that experience was like?

P: It was a little bit hard... at the onset and it quickly destroying me, in a way, so, you know, it was a little bit hard, but because I have a very good support group, you know, my husband listened to me and my friends were very good about listening and offering that shoulder that it was... and I have, you know, I’m not sitting at home doing nothing to dwell on it. You know, I’m still able to get up and go to work every day to take my mind off of it, and of course, the people at work have been very supportive about it and I’ve also found friends that also have issues similar to mine as far as, you know, they have autoimmune disorders and have had to deal with things that we can all commiserate together and they’ve all been so supportive that it’s been easier for me to take. I’m still... It’s still hard. There are days when, you know, I might cry about it, or I do a lot of cursing because I drop things a lot and it bothers me that, you know, so I have little curse-out sessions where I’m either yelling or you know, sit in my car and yell but it makes me feel better. I get it out and I think often talking about it. You know, I don’t bottle it up and hold onto it. I talk about it with people. It’s, you know, easier to take. And, you know, I have to keep telling myself, there’s not much I can do about it. You know, I have to live with it. It sucks. It really does, but what else can I do? I don’t have a choice.

I: Ok. Yeah. I guess... Yeah. I wonder how you see yourself in the immediate and long-term future?

P: I guess I’m optimistic in a way that I keep hoping that, because this disease has an active period and an inactive period, that I will get to that point quickly, soon, to be inactive and then things may go back. I’m hoping things will go back to close to
normal. I might be deluded, a little bit (laughs) in that sense, but like, for instance, this new medication that I’ll be... this chemo treatment I’m going to be taking... I’m hoping that it will do its job. I’m really hoping that it will set me to that point where... maybe even do a reversal like some people have, where I will get maybe some use of my hands back, or better use of my hands back. I won’t be... My legs won’t be as tight, you know, or hurt as much when I walk, so I’ll have a little bit more normalcy back, and then I can go on, and maybe go back to doing some of the things that I like to do, like the gardening and the walking and, you know, things like that. I would like that to be in the near future. The long term, I’m hoping that, if it does go into some sort of remission or something that I can live very long time and not have things happen and just go back to normal, or as close to normal as I’m going to get, my “new normal” as they call it. I’m hoping I’m not deluded (laughs) in thinking that, because, of course, like I said these people in my chat groups have been going on, you know, some of them have been going on decades and I don’t know if they’ve lived with it this long, or their pain and suffering has continued that long, or some inching back, or if it’s a result of maybe they didn’t get diagnosed early enough, or there are multiple issues that is causing them, you know, all the discomfort, so... I would like to see a rosy future for me. I’ve got plenty of time left.

I: Yeah. I wonder about “new normal”, what that means for you.

P: Well, I took it from somebody else who blogged about it and when I was reading his blog I wanted to see, you know, ‘cause it spanned over three years, or four years, or something like that, where it described his symptoms and, you know, I questioned him about it, like his hands, did they ever go back to normal, and he used the phrase “new normal” because, while there were things he couldn’t do before like play golf and ski, he now could, after his treatment was over, but he never went back to quite the same “normal”. I don’t think he got full use of his hands back as far as the way they were prior to scleroderma, but, you know, he could finally grip the golf club and he could finally ski, ‘cause he wasn’t tired or didn’t hurt and his feet would actually fit back into the ski boot, so for me, I guess the “new normal” is I’m hoping... Well, as much as I’d love to get full use of my hands back, I don’t know if that will be... I don’t know how much damage has actually already been done, whereas they might be a little bit better, but may not be exactly the way they were. And maybe all the skin on my face might not go back to the way it used to look before. It might still be tight (Line goes silent). ...but unfortunately I have to come to the reality that it probably will not happen but maybe I can get a little bit closer to the way it was.

I: Ok. Thank you. Yeah, I guess we’ve covered pretty much all of the main points. I wonder if there’s anything that you find that’s been personally important for you in your experience, or that you’d like to share?

P: I guess, you know, it’s important, I think, for people to really pay attention to their bodies and if something’s not right, don’t sit around and.... I know some people, like I said, fears set in or they may not have... to worry about the insurance or something,
so... It could be difficult. I know there are times when I really don’t want to do something... I really don’t want to go to the doctor ‘cause I’m afraid of what they are going to say, but, you know, if they tell me I have to do something, then I have to do it, because otherwise, it could be ten times worse, and I’d rather try and get it fixed now, or do the best that I can now, than let it, you know, happen and you know, if something’s wrong with my heart, obviously, I mean, I’m too young to die early. I need to get it fixed. I need to take care of it. So it’s important for people to go, and of course the other problem is good access to health care.

I: Right.

P: I’ve been lucky so far in finding doctors that are very educated and very smart and knowledgeable in my disease, but some people may not live in the area where they have access to health care and good doctors, or they have to travel too far and that can be difficult, so, I know, for me, I don’t like to drive long distances, so to go to a doctor that’s too far might be a little bit out of the question. I mean, granted I have people who would drive me, but, you know, travelling for an hour or two, I mean I’ve heard of people travelling for like four hours to go to specialists and, you know, with as many doctors appointments as I have, that’s just too much, especially since I work full time, that’s a lot of drive time and a lot of... something, especially if I have to rely on somebody else. But I do think it’s important that we pay attention to our symptoms and be sure our doctors listen to us. I also have been lucky that my doctors pay attention. They have a good bedside manner, they listen and they care. I’ve heard other people have doctors that, you know, kind of shoo them off, don’t want to listen, don’t really pay attention and maybe they’ll miss something. Maybe somebody said something important and because they were so busy being arrogant about it, they missed the important thing and it would have been the “aha” moment, where the doctor can go: “Aaah! Ok! Now I know what’s wrong” or, you know: “Now I know... oh! We need to fix that!” So it’s important really to have a good relationship with your doctors and, I know, it’s not always easy. It’s been easy for me so far, knock on wood, more superstitions, but I know there are times when I’m always afraid. You know, what if I’m not going to be able to find that person, that doctor that’s going to listen? Or, will this doctor help me? I know when I talk about moving... My husband was military so I’m used to moving and we talk about when we finally settle down somewhere permanently, one of the things that I have to now look for is good health care. So I look up in our insurance all the doctors that are available in a certain specialty and maybe I’ll research it before I decide to go to that city, just because, you know, (laughs), if I’m going to stay there I need to have access to local and good health care, so it’s now become one of the important things on the list, like jobs, housing, medical care so...

I: Yeah. I think a few people talk about the importance of doctors in how the whole experience is and some have had trouble being diagnosed or having doctors who aren’t listening etc. and it is a very important...
P: I was in an area that's actually close to one of the research centres, so I guess people who have been trained and it's a major university that... and I don't live that far, I mean it's a couple of... probably an hour and a half or so, but it still has provided my area with knowledgeable doctors that have heard of the disease, that have had experience with it, training, that kind of thing, or just the knowledge to, and the ability to research it. Plus, they also have local access to maybe more experts, whereas a doctor maybe in North Carolina or somewhere in Texas or something like that might not be familiar with it, might not be close to a centre where they can ask people questions and things like that. So... And I guess that there's always the possibility that I would have to go to (university), but at least the option's there, as opposed to having to travel cross-country somewhere where you have to get on a plane and, you know, it can get very expensive. (university) is more about gas, (Laughs) and driving but it's still feasible, if it came to that.

I: Right.

P: So, I'm lucky in that sense.

I: I guess I'm thinking you were also saying that you were lucky in terms of having a good social support and people that you can talk to. I was wondering... I guess a few people have brought that up as something important that has been helpful and others have also mentioned on the (sub)??? (30:29) side not wanting to talk to people around them too much about it and I was wondering whether... I guess the question is some have found talking with psychologists more useful while others find that they have a good support network and would rather communicate with them and I was wondering what your experience had been like?

P: I find it helpful to talk to my friends. My aim is to educate people. You know, they obviously will see a difference in the way I look from when they knew me before and when they know me now, so they do know something is up. Two, education is important, you know, for people, because it may not necessarily... They always say: "This disease, you know, you look healthy, you look fine and how could you be so sick?", or things like that, so, or: "You don't look sick", so, I guess, I'm a little vain, you know, I would like the sympathy, so I guess the more people who kind of know and understand, they can kind of sympathise with me, especially when I say I can't do things, or I don't want to something. They want to go somewhere I don't really want to go, I can't go. If I hid my reasoning, they would think I was making excuses, that I didn't want to hang out with them, or: "Oh! She never wants to go anywhere and do anything," but now they would know why. "Ok", they say, "maybe we can do something else, a little bit more your speed." My friends have also been very helpful, because every day it's a new experience and there are bad days. There's days when I hurt. There's days when I just... you know, maybe I don't want to get out of bed, because I'm just tired and it's nice when I can kind of say something to somebody, you know, a friend, say: "Yeah. I had a really bad day yesterday", and they can, you know, offer that shoulder. Plus, like I said before, if you bottle it up, it will eat away at
you, so it’s good to get things out, because your friends, if they are good friends, then they’ll listen to you. I mean if you complain too much, I can understand, but, you know, it’s not an every day thing. I don’t consistently complain, so... But they’re also very helpful, you know. I have a very good friend. She’s my shoulder to cry on and everything so when we do go somewhere, she knows my limitations, if we go to a restaurant and maybe, if I drop something, she’ll offer to pick it up, ‘cause she knows I have trouble gripping things off the floor, or picking things up, because they’re heavier, so she’ll offer to do those things. So that’s nice. And, you know I don’t look lazy now, because it’s not that I don’t want to do it, it’s because I can’t do it anymore. I have other friends who... I’m learning that they have similar issues and they’re happy to find someone that they can talk to about it, that has experience with it and maybe... I’ve actually got a lot of friends that end up going to my same doctor. So I can give them, you know... I can give them tips on the doctors themselves, the whole process of what the doctor’s going to do, because I’ve been through it, things like that. So they’re very grateful. So, you know, it’s a nice give and take. I know some people are shy about it. They don’t... But that’s their personality. And I think it’s difficult for some people to express themselves to others, especially when it’s something negative, like disease. And I’ve also heard people say that they don’t have a supportive family or friends, you know, or maybe they’re just kind of segregated. Maybe they don’t have a lot of friends but their family’s very unsupportive or in denial about it.

I: Right.

P: And I can’t say my family is perfect about it. I know my Mum can be a little bit ignorant about it. She’s just not educated about it. I tried to educate them, so she’ll say things some times that irritate me, but they have my best interests at heart and I just kind of tell them this is how it is and, you know, you have to get used to it. There’s no two ways about it, and, you know, this is how I have to eat now. This is what I, you know... I can’t have the big meals anymore. It takes me longer because I have to eat slower. You know, get used to it. If you don’t like it, then I won’t come over anymore. And you know, my husband, he’s been very helpful, as far as lifting things for me and trying to find ways for me to adapt, like the little grabber thing that he bought for me and while he may think that it’s funny to do certain things and joke about it, I think deep down it’s a little difficult for him to realise that... You know, I was the one that always took care of him, and now, he kind of has to take care of me and I’m limited to what I can do. But he also sees that I can still... I still try. You know, I don’t just sit around going: “Oh! I can’t do it anymore.” You know, as far as like cleaning the house or cooking, or something like that... And sometimes I try too hard and I wear myself out, but I still make the effort. And I hope he appreciates that, so... You know, I guess I’m lucky so far, that I’ve got a good group of friends and family and I always feel bad for the people whose husbands and kids and family and parents just don’t support them, don’t believe them. They think they’re making it up, but, you know, it’s ? (36:10) It really is.
I: Ok. Well, we’re almost coming to an end. I was wondering if there’s anything else that you would like to add, or that you feel that’s important that I haven’t asked, or that we haven’t touched upon?

P: Well, I’m just hoping that in some point in the future... I mean, I know they’re trying... It’s a shame that this disease, because there isn’t as many people, but there’s more people, I think, than they think, who have it, where all the money is going to larger diseases and all the research is going there. You know, they’ve done enough, no offence to the cancer people, but they’ve done enough research, they’ve got a lot of treatments, you know? Maybe it’s our turn. Shift the money our way! (Laughs.) We need some more help. I really don’t like the fact that I’m limited to the medications I can take and even those medications may not have been tested so much as... They just, that’s what they use, and... so far as this is how... what it’s done. And I know they’re starting to get more research and starting to get more money but, you know, it’s very difficult when you have a disease that they consider rare, but it’s not as rare as you’d think. There’s got to be... I think there’s at least a hundred thousand or couple hundred thousand people, if not more, and maybe more of them have it. Just nobody knows, because they’ve been misdiagnosed, or they haven’t been recorded, or something, so they, you know, I really hope education people speak up about it and educate people and, you know, get them to either donate, or get them to realise, you know, do more research and focus on... the researchers to focus on something like scleroderma rather than something that’s been focused on so much that, you know, they’ve got the money and the time and they have some of the answers already. So, you know, it would be nice. I know they’re doing some like PSA’s and things like that but... because we need to get more face time with people and with the public, so...

I: Ok. Great! Is there anything else that you’d like to add?

P: No. I think that’s it!

I: Ok. Well, thank you so much!

P: You’re welcome!
Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.
1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

• the content of the paper falls within the scope of the Journal
• the methods and/or sample size are appropriate for the questions being addressed
• research with student populations is appropriately justified
• the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via http://www.editorialmanager.com/bjhp/. You may like to use the Submission Checklist to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

5. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.

• **Statement of Contribution:** All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. The 2-3 (maximum) sentences for each point should identify existing research knowledge relating to the specific research question/topic and a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.

• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

• Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials (http://www.consort-statement.org).
What is already known on this subject?

Chronic illnesses can profoundly impact on essential life domains and cause significant psychosocial distress. Being diagnosed with a chronic condition is usually a life-changing experience and the challenges faced by someone with a chronic illness are complex and ongoing, requiring the individual to constantly adapt to developing symptoms and circumstances. Individuals who are diagnosed at a young age must negotiate more life stages and have more time ahead of them to adapt to living with the illness and to managing symptoms than someone older with a shorter life-expectancy.

What does this study add?

- Provides a theoretical framework with which to understand the experiences of people who were diagnosed with a chronic illness when they were young.
- Supports and adds to previous research and provides new insights into the experiences of people who were diagnosed with a chronic illness when they were young.
- Highlights how illness influences identity and development and discusses clinical implications.
Research Report 2:

‘Closing the gap’: Personal meanings among psychotherapists working with clients with long-term health conditions.

Abstract

Background: While there is a substantial body of research on clients’ experiences of chronic illness, there is a dearth of qualitative research examining chronic illness from practitioners’ perspectives.

Aims and Objectives: The aim of this study was to explore how practitioners make sense of clients’ long-term conditions. The objective was to develop a better understanding of long-term conditions from the perspective of psychotherapists. For this purpose the research asked: How do psychotherapists make sense of their clients’ long-term conditions?

Method: Five female therapists who had worked with people with long-term conditions for a range of 3-27 years were interviewed. Data was analysed using an Interpretative Phenomenological Analysis approach.

Results: Two superordinate themes emerged from the data analysis: No ‘them’ and ‘us’ and Redrawing boundaries. Participants in this study anchored their understanding of their clients’ experiences and of their therapeutic work by drawing similarities between themselves and their clients and non-health-related distinctions with other client groups.

Conclusions: Dealing with chronic conditions in a psychotherapeutic context is a process that requires psychotherapists’ understanding of their clients’ experiences and of their therapeutic work together. This study elucidated some psychological and therapeutic processes relevant to practitioners working with people with long-term health conditions.

Keywords: long-term/chronic; illness/condition; therapist; IPA; qualitative.
Introduction

Chronic or long-term conditions are health problems which, at present, cannot be cured and which, according to the World Health Organisation (WHO) (2002), are the leading cause of mortality, morbidity and disability worldwide. In England, more than 15 million people are living with long-term conditions, a figure which is expected to increase over the next decade (Department of Health (DOH), 2013). Indeed, the incidence of chronic illnesses is increasing globally and is expected to be the main cause of disability by 2020 (WHO, 2002).

Chronic illnesses vary greatly in terms of symptoms, severity and progression and can profoundly impact on essential life domains including education, employment, financial opportunities and relationships (Lubkin & Larsen, 2006). In addition, chronic conditions are often associated with increased difficulties in psychosocial functioning including anxiety, depression, cognitive strain, social isolation, self-esteem, self-concept and interpersonal relationships (Lubkin & Larsen, 2006). Diagnoses are usually life-changing and require individuals to learn to recognise and manage symptoms, deal with flare-ups or illness exacerbations, use medication, treatments and services effectively and develop strategies to manage the psychosocial consequences of the illness (DOH, 2001). Whilst long-term conditions cannot be cured, they can often be managed through medication and other therapies (DOH, 2013).

Counselling psychology emphasises the importance of not medicalising or pathologising clients' difficulties. However, clients with chronic illnesses are often referred to therapy for psychological difficulties which have been precipitated by a medical diagnosis. Indeed, a feature that often distinguishes clients with chronic illnesses from the general clinical population is that they are a client group which, prior to diagnosis, has not been in contact with mental health services (Sanders,

6 The terms “chronic” and “long-term” are used interchangeably throughout this paper, as are “illness” and “condition”.
Surawy, Zahl, & Salt, 2010). Rather, they are typically clients who are experiencing distress owing to the onset of a life-changing and medically ‘framed’ condition.

There is ample evidence that psychological therapy can improve the quality of life and alleviate the distress of people suffering from chronic illnesses (e.g. British Association for Counselling and Psychotherapy, 2005; Petrie & Revenson, 2005). Rumble (2012) emphasises that whilst it would be irresponsible not to take medical diagnoses into account in therapy, “welcoming diagnosis to therapy should be tempered by an ethical commitment to go beyond diagnosis to the client” (p.116). Counselling psychology’s emphasis on depathologising psychological difficulties seems especially pertinent when working therapeutically with clients with chronic illnesses. This means viewing problems as a part of human experience and as ways of coping with life’s difficulties and focusing instead on understanding the dynamics and processes that shape individual experience and the meanings that psychological difficulties have for individuals at particular junctures in their lives (Strawbridge & Woolfe, 2003). Furthermore, it seems paramount to understand whether and in what ways therapists working within a context dominated by a medical model can uphold counselling psychology values such as focusing on wellbeing rather than pathology or maintaining a collaborative rather than expert-client therapeutic relationship.

Whilst there is abundant literature on the difficulties that people with chronic illness may grapple with and some literature on the experiences of practitioners who themselves are diagnosed with long-term illnesses (e.g. DeMarce, 2007; Kaschak, 2001; Maggio, 2007; Sollod, 2002), there is a dearth of literature pertaining to therapists’ subjective experiences of working with clients with long-term conditions. Understanding how therapists make sense of their clients’ experiences and conditions and how they reflect on their work with this client group may help to elucidate some psychological and therapeutic processes relevant to practitioners’ personal and professional development. This is important, as it may shed light on how practitioners approach their work and it may inform new therapists who wish to work with this client group.
Qualitative methods are said to enable unique personal accounts to be explored in detail, yielding new and profound insights into participants’ experiences (Yardley, 2000). Therefore, this research focuses on broadening the existing literature on this topic by adopting a qualitative perspective to explore in depth what positions therapists adopt when working with people with chronic illnesses and how they make sense of their therapeutic relationships and endeavours. Upon considering different qualitative methods, an Interpretative Phenomenological Analysis (IPA henceforth) approach to data collection and analysis was considered the most appropriate for the purposes of this study. Firstly, IPA has been described as “especially useful when one is concerned with complexity, process or novelty’ (Smith and Osborn, 2003, p. 53), all of which are relevant in the exploration of practitioners’ understanding of long-term conditions. Additionally, Brocki and Wearden (2006) explain how our understanding of illness has shifted away from the biomedical model of illness, where bodily processes where assumed to “map onto a predictable illness experience in a fairly simple way” (Brocki & Wearden, 2006, p.88), towards an understanding of illness as a more complex and constructed experience. Consequently, IPA is considered particularly relevant because it allows the exploration of individuals’ subjective perceptions, interpretations and meanings regarding illness and bodily experiences and of the dynamics and processes that shape their experiences and hence, of how their experience is understood and constructed (Brocki & Wearden, 2006). Furthermore, IPA aims to capture and explore contextualised and detailed accounts of the individual participants’ personal experiences and the meanings they assign to them (Eatough & Smith, 2008; Reid, Flowers, & Larkin, 2005). IPA is informed by phenomenology, hermeneutics and idiography (Smith, Flowers, & Larkin, 2009). Phenomenology aims to examine lived experience and the unique perspectives and meanings that individuals derive from their relationship to the world. Hermeneutics is concerned with the theory and processes of interpretation. Idiography emphasises the particular rather than the general, meaning that it aims at a detailed understanding of how particular significant lived experiences/phenomena have been understood by particular people in particular contexts (Smith et al., 2009). Therefore, and to conclude, IPA aims to explore in as much detail as possible the participants’
experiences and how they make sense of them, in order that the researcher may develop an interpretation of the participant’s experience (Smith et al., 2009).

The aim of this study was to explore how psychotherapists make sense of their clients’ long-term conditions. The objective was to develop a better understanding of chronic illness from the perspective of psychotherapists, which could provide new and richer understandings of the perspectives that inform psychotherapists working with clients with chronic illnesses. Additionally, this could help to develop new ways of understanding and dealing with chronic illnesses psychotherapeutically. For this purpose, the research asked: How do psychotherapists make sense of their clients’ long-term conditions?

Method

Participants

A purposive sampling strategy was employed in order to explore therapists’ particular perspective on clients’ long-term conditions (Smith et al., 2009). This involved selecting participants who shared a particular lived experience, for whom the phenomenon being studied was meaningful and who therefore could “grant access to a particular perspective on the phenomena under study” (Smith et al., 2009, p. 49). The sample was homogenous. That is, participants were similar enough to represent a specific perspective in order that psychological variability and convergence within the sample could be examined (Smith et al., 2009). Additionally, a small sample was chosen to allow engagement with the idiographic and the particular in order to gain indepth insight into the phenomenon under study.

The participants were five female therapists whose ages ranged from 28-58. They had approximately 6-36 years of clinical experience, out of which they had worked specifically with people with long-term illnesses for a range of 3-27 years. The participants worked within a secondary care context and followed a primarily 3rd wave
CBT approach to therapeutic work. The participants predominantly worked with clients whose psychological difficulties/presenting problems were secondary to their health condition. Participants were recruited through snowballing.

**Ethical considerations and confidentiality**

This study did not require ethical approval from the University of Surrey’s Faculty of Arts and Human Sciences (FAHS) Ethics Committee. The researcher and her supervisor consulted the ethical flowchart published by the Committee and confirmed that: deception would not be used in the study; the participants were not considered vulnerable and were not current members or staff of the university; the questions in the interview schedule could not be deemed to be sensitive or offensive; and issues of confidentiality and anonymity would be guaranteed.

**Procedure**

Participants were informed of the purpose of the study, that their participation was voluntary and that they could withdraw from the study at any time up to the stage of data analysis (see Appendix A). Written, informed consent was obtained from all of the participants (see Appendix B) and following the interview, participants were provided with a debrief form explaining the purpose of the research (see Appendix C).

It was agreed that in order to ensure confidentiality, data would be securely stored, identifying information would be anonymised and participants would be provided with pseudonyms. Participants were also offered the chance to review their interview transcripts and to remove information which may violate their confidentiality.

Interviews were chosen as a method of data collection because “the real-time interaction with the participant gives major flexibility for the researcher in facilitating the participant in exploring their lived experience” (Eatough & Smith, 2008, pp. 187-188). Data was gathered from one-to-one, in-depth, semi-structured interviews.
lasting approximately 40 minutes and participants were asked to complete a demographic information questionnaire (see Appendix D). The interview schedule was based on existing literature and the researchers' personal interests. The questions aimed to explore therapists' perspectives on clients with long-term conditions and their experiences of working with them and asked participants: what was their understanding of chronic conditions; what they thought it was like to have a chronic condition; what it was like to work with clients who had chronic conditions; whether they could compare clients who did have chronic conditions with those who did not; and what they thought the future was like for people with chronic conditions (see Appendix E).

Smith et al. (2009) view independent audits as "a really powerful way of thinking about validity in qualitative research" (p. 183). Mini independent audits were conducted with the researcher’s supervisor and a peer using an extract from a transcript, in order to ascertain whether the researcher’s annotations had some validity/credibility in relation to the transcript (Smith et al. 2009). In addition, the researcher has attempted to contextualise the sample, provide a clear and coherent account of the research process and to provide extracts from each participant to illustrate each theme in line with Yardley’s (2008) criteria for validity and quality in qualitative research.

Analysis

Interviews were audio-recorded, transcribed verbatim and analysed using the steps of IPA described by Smith et al. (2009) and Smith, Jarman and Osborn (1999) outlined below (see Appendix F for an example of an interview transcript). Firstly, each transcript was read several times in order to focus on the participant’s experiences. At this stage, the researcher aimed to note and bracket off initial observations, assumptions, connections and ideas in order to focus on actively engaging with the data.
The second step involved generating exploratory descriptive, linguistic and conceptual comments, which were annotated along the right margin of the transcript. The researcher aimed to generate comprehensive and detailed comments which examined semantic content and language use and to identify specific ways in which participants understood different issues. Some of the notes had a phenomenological focus describing participants' personally salient experiences and the meanings they ascribed to them, while interpretative notes focused on how participants made sense of these phenomena. The context in which the participants’ experience was embedded was also considered.

Next, the exploratory comments generated in stage two were analysed to identify and develop emergent themes/concepts. The researcher aimed to create themes which captured and reflected both the participant’s account and the researcher’s understanding of the participant’s account. These were annotated along the left-hand column of the transcript.

Step four involved looking for patterns and connections which drew together the emergent themes and developing a structure which incorporated the most salient/interesting aspects of the participant’s account. Related themes were grouped together to create ‘super-ordinate’ themes and were consolidated in a table.

The steps outlined above were repeated with each transcript, while aiming to treat each case individually and to bracket the ideas which emerged from previous analyses. Finally, once each transcript had been analysed individually, patterns, connections, idiosyncrasies, recurrent themes and shared higher order concepts were sought across cases in order to develop a master list of themes which would contribute towards a better understanding of the participant’s experiences (see Appendix G).
Although all participants varied in their demographic backgrounds, the data yielded some commonalities. Two superordinate themes were identified in the analysis. The first superordinate theme, No "them" and "us", presents an account of participants’ perspectives and understanding of the similarities between themselves and their clients. The second superordinate theme, Redrawing boundaries, describes participants’ perception of their clients (and by implication themselves) as different to ‘traditional’ mental health clients in non-health-related ways and the implications of this distinction for the therapeutic process, relationship and outcome. These superordinate themes are developed below.

1. No ‘them and ‘us’

Participants described understanding their clients’ conditions and difficulties as either experiences that they could one day possibly experience themselves, given that they could one day be faced with a similar diagnosis, or as experiences that are inherently human and thus inescapable, and which they were therefore certain that they would share with their clients at some stage. Participants also described how a large element of their work and their understanding of their clients was based on a focus on embodied experience and on focusing on the person in therapy rather than on the condition. These subordinate themes are described in more detail below.

1.1 Focus on a shared vulnerability to illness. Participants emphasised practitioners’ vulnerability to illness and the sense that therapists are not exempt from developing chronic conditions. They felt that this shared vulnerability and the prospect of experiencing something similar, in the future, was particular to working with this client group and facilitated a sense of closeness and relatedness:

"It could be, you know, any one of us and maybe we do have chronic health conditions ourselves and just the interesting feeling that it's really not a 'me and
them' kind of thing [...]7. It could come along any moment and we could have a pain, have a break, you know, get a gastric problem [...] and I quite like that, really, that it's not something that I'm never going to get. It's a kind of 'we all are a bit vulnerable to it' and have that potential to have a health problem" (Susan).

Dawn highlighted that this sense of closeness and vulnerability was more pronounced when working with people with chronic conditions than with other client groups and that therefore, therapists working with people with chronic conditions were not buffered by the belief or knowledge that they are 'safe' from their client's experiences. This lack of safe distance was described as requiring that therapists working with this client group reflect on their own fears about illness and death and confront their vulnerabilities:

"In mental health, trainees often have quite a secure sense that they would never go mad in the way that their patients are mad or in learning disabilities, you know, they kind of know they missed the boat on that and it would never happen to them, whereas most of the conditions that we work with here are things that you could discover you've got tomorrow [...] and I think one has to face that sense far more as a therapist, that actually the likelihood is that one of these conditions will get us, sooner or later" (Dawn).

1.2 Focus on shared humanity. In addition to emphasising a shared vulnerability to illness, and consequently the potential for experiencing something similar to their clients in the future, participants also emphasised similarities in lived experiences based on the shared experience of being human. Paula reflected on our shared mortality: "Life is a terminal condition" and emphasised that "the existential stuff about 'what do we do while we are here?' is crucial for everybody". Additionally, participants drew parallels between their own and their clients' experiences based on an awareness that illness, suffering, and death are inexorable experiences which are

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7 Brackets [...] indicate that material has been omitted.
not exclusive to their clients but shared by every human being. For instance: "It’s just a part of life really" (Susan).

This awareness of a shared existential trajectory placed therapists on the same journey as their clients, facing the same obstacles or challenges, thus emphasising a shared humanity, rather than drawing distinctions between themselves and their clients based on their health status. In the extract below, Sandra described how she viewed this shared ‘fate’ and humanity as ultimately true in any therapeutic relationship but suggested that, when working with physical conditions, it was clearer and could thus be addressed more openly and directly:

"I think the honest bit about chronic conditions is, you know, you do feel you can say: “Ok, we are working with a human condition here” [...]. This is life. This is what it is to be human. We are all going to die one day. We’re all going to have limits at some point. We can’t deny that, that’s the elephant in the room. Just deal with it. Really look at that [...] and I think that’s across the board for chronic conditions, psychological distress, mental health conditions. It’s the same idea really. But I think you get to work with it more actively – transparently perhaps, with physical health conditions” (Sandra).

1.3 Focus on shared embodiment. Similarly, participants described the importance of “the groundedness of human experience in the physical body” (Sandra), describing embodiment as an additional aspect of the shared human experience and consequently, its importance in helping to make sense of clients’ difficulties. Participants emphasised the importance to them, as therapists, of being able to address the connection between mind and body and shared the view that embodiment was more accessible or easy to engage with when working with chronic illness:

“One of the main reasons that I wanted to work in health is that idea that it’s not a mental... it’s not just a kind of psychological mental health issue. It’s about being able to link up body and mind and, you know, people’s coping, people’s physical
state and having to have a formulation or an understanding that can hold the two parts of your self together. I enjoy that about my work a lot and that’s why I got into it, you know. I think that’s key and different about health.” (Susan).

Clare reflected how working with people with chronic conditions “requires a lot of attention to detail in their own bodies”, while Paula emphasised the importance of both therapists’ and clients’ “experience of the body and our way of being in the body and our way of engaging with the world through our body”.

1.4 Focus on the individual rather than the illness. Participants described focusing predominantly on their clients rather than on the conditions and how this focus on the individual is required in order to understand their experience. Sandra highlighted: “actually people are just people, [...] whatever label they’ve got themselves or condition they have – there’s a knack to actually seeing the person and not the condition” (Sandra). Susan explained how she liked getting to know the person and “the challenge of understanding what people are like before, what they’re like now and what they want to be in the future”. Clare described the relevance of “their own personality” and Paula described the importance of “an identity not grounded in the illness”. When asked about the experience of having a chronic illness, Dawn explained that “there are as many ways it can be as there are people who have it,” which was echoed by Sandra who emphasised that “you can have a condition and live your life or experience it in two hundred different ways”, highlighting how conditions are experienced differently depending on the person’s unique characteristics.

When asked about her experience of working with people with chronic conditions, Sandra explained that she did not make such a distinction. Her perspective of her work or her clients’ distress was not married to the label or concept of illness, illustrating once again the participants’ emphasis on the notion of sameness rather than difference. Sandra also implied an ethical or moral objection towards viewing clients through a generalised illness-focused lens that put all clients in a “chronic conditions box”. Placing something in a box implies setting something apart, thus creating a distance or
separation, whereas Sandra would rather focus on the common experience of being a person:

Researcher: “What's it like working with people with chronic conditions?”

Sandra: “I guess exactly the same as it's like working with people (Laughs). I just work with people. I don't — I have no idea what it's like working with people with chronic conditions. It's not something that enters my head, to be honest. I just think I work with people who have actually got stuck in their life [...] So yeah, I try not to think — I don't have — I can't put everybody I see into a chronic conditions box. It just doesn't feel right actually, I can't - I can't do that. I don't want to do that”.

By refusing to engage with her clients by means of a differentiating categorisation (i.e. clients with chronic illness) which “doesn’t feel right”, Sandra bridged the separation between ‘normal’ people who suffer because they have ‘got stuck’ and are distressed and ‘people with chronic illness’. That is, between ‘us’ and ‘them’.

2. Redrawing boundaries

This superordinate theme describes participants’ perception of their clients as more robust and resilient than ‘traditional’ mental health clients and their views regarding the implications of this for the therapist and for the therapeutic process, relationship and outcome.

2.1 Drawing the line between insiders and outsiders. Participants portrayed their experience of working with people with long-term conditions as different on account of viewing their clients as more robust, functional and resilient than clients with mental health difficulties. Susan described clients as having “A massive range of coping abilities” (Susan) and several participants emphasised clients’ positive attributes (e.g. resilient, less vulnerable, resourceful, competent, emotionally stable,
more in control), explaining how their clients were people who had functioned well prior to their illness but who needed help adjusting to or managing their conditions:

“A lot of the people don’t have mental health histories, so it’s something landing in your life that is really difficult to handle, often in a context of a fairly resilient, robust person who has a life already” (Paula).

Dawn described clients as having more insight and thus being more capable of recognising when they needed help: “People with long-term conditions, they get it. They know when they need a bit more help and when it’s going be important to make something happen”, while Susan described clients as “people who wouldn’t traditionally see a psychologist” thereby implying a difference in characteristics between clients who would and who would not ‘traditionally see a psychologist’.

While most participants differentiated between client groups in terms of psychological strength and resilience, Dawn also distinguished between them on the basis of her own personal feelings regarding clients’ difficulties. Dawn described how her own fear of mental illness made it harder for her to work with mental health clients and how she found it painful to work with people whom she perceived as more vulnerable and less responsive to behavioural interventions than clients with chronic illnesses. In this way, she not only drew a line between client groups, she also drew a line demarcating the work that she is and is not comfortable doing:

“Death and illness don’t frighten me nearly as much as going mad, so there is a sense in which this is much easier than working with bipolar disorder or schizophrenia or psychosis [...]. I find the pain of working with people who are struggling with that sense of, you know, total vulnerability and out-of-controlness much harder than working with people in the, you know, very difficult stages of their illness or towards the end of life” (Dawn).
2.2 Redefining therapeutic possibilities. Viewing their clients as different to traditional clients had implications which participants described as advantages of working with people with chronic conditions, as opposed to other client groups. The differences they described between their clients and other clients were non-health-related and not only affected the nature of therapy and the therapeutic relationship but were described as personally meaningful and relevant to the participants as therapists. For instance, Paula described the personal importance of having a sense of agency and being able to “do” something and work “swiftly” with relative ease and compared this with her past experience of working with mental health clients, where she found frustrating the restrictions on what she could ‘do’ or achieve with clients:

“A lot of the time it feels like there is really a lot you can do, very swiftly, with relatively little work, almost to help process the transition and redrawing the compass of where you’re going in life, so I think you can do a great deal very swiftly, whereas in mental health, I felt that clinical psychologists were often just given the most difficult patients, who weren’t the ones you could do the most with. And I found that very frustrating [...] So I like having opportunity to work swiftly. Lots of these people - it is about working swiftly, more so than in mental health [...] That’s the really important part of it, actually” (Paula).

Similarly, Dawn described clients as having more agency and taking action or progressing in ways which exceeded her therapeutic expectations and goals, consequently making working with this client group ‘interesting’, ‘exciting’ and ‘inspiring’:

“The work that we do, because mentally they are stronger, quite small interventions go a really long way, so it’s really exciting to see how a small piece of work with someone they pick up and run with and they do things we would never have predicted or exactly been aiming for, but nevertheless it works for them and so there’s... I suppose, yes, there is that, the way that people with longterm
conditions pick up and run with stuff is really inspiring (laughs) so I love that” (Dawn).

Participants viewed establishing a relationship, building trust and working collaboratively with clients with chronic conditions as more “straightforward” (Susan), which enabled therapeutic work to commence sooner and progress faster than when working with mental health clients:

“It’s much easier to work alongside and in collaboration with people with longterm conditions than it is... Most of the work in mental practise is about trying to build a relationship. You can work for years to build a relationship to get to a place where you can start to work with someone and people with long-term conditions, you know, within a session sometimes, certainly within a couple of sessions you’re off and at a very good pace in which the trust that enables you to start doing something really quite exciting - so I never was much into deferred gratification (laughs)”.

In the extract above, and echoing Paula’s comment about valuing “the opportunity to work swiftly” and finding not being able to “do” a lot “frustrating”, Dawn alluded to the sense of excitement and gratification which she derived as a therapist from what she viewed as therapeutic progress, implying that whilst the more long-term process often involved in mental health work would be frustrating to her, her own sense of achievement and “gratification” was more easily reinforced when working with clients collaboratively and at a “good pace”. On a related note, Clare described feeling frustrated with some clients who “appear to be at pains to explain [...] how they can’t possibly do anything and be very closed [...] to actually trying”, referring to her frustration when things aren’t ‘done’/achieved therapeutically.

Another difference which participants viewed as important was that, while their clients’ conditions were long-term (i.e. medically there was no fix or change possible), behaviourally there was often still scope for change and this made dealing with the
‘stuckness’ and hopelessness of their clients’ physical health easier to manage for the therapist. For instance, Paula described how being able to help her clients in some respects brought hope or a “sense of possibilities” which made her inability to help them in other respects easier to bear:

“Sometimes we can do a lot to help them and sometimes we can’t, but there is the sense that behaviourally there is quite a lot of potential, so it’s easier to be there with the sense of possibilities for change” (Paula).

2.3 Different challenges and demands. While participants described some of the differences of working with clients with chronic conditions as favourable to themselves as therapists and to the therapeutic process and outcome, some participants explained that not all clients fall into either a mental health or a physical health category, “a lot of the people who I see [...] do often have mental health problems too” (Susan), and others may have more than one condition, which makes the work more complicated: “people may have 2 or 3 conditions that kind of act together [...] so that can be really difficult” (Dawn). Therefore, things are not always so straightforward. Indeed, some of the participants’ clients presented both physical and psychological difficulties, which Susan described as a combination which felt “quite challenging at times, you know, having to deal with such a lot”. Clare described how different personality types, or mental health difficulties experienced prior to the illness, may interact with and compound the condition, making the therapeutic work more complex:

“If you’ve got someone who’s always been very anxious or very avoidant prior to having whatever condition it might be, then you might get into interaction there where it feeds in even more to that... that type of personality type [...] I think it gives that extra level of complexity and you have to take into account the different aspects of the physical condition as well as the psychological and how those two, you know, develop together” (Clare).
In addition, the clients’ physical condition may require interventions to be tailored to their physical needs or abilities. Therefore, in cases where clients presented both physical and mental health difficulties, therapists were faced with additional challenges and demands:

“There can be a lot more complications in trying to work with the two aspects together [...] You do have to tailor it rather differently to meet the needs of... given the physical complaints that people might have” (Clare).

Furthermore, participants described the challenges that arise from working with clients with whom they share a sense of vulnerability. On the one hand, this was described by most participants as enabling the therapist to relate with the client in a more compassionate, respectful and collaborative way. On the other hand, it was also described as having the potential to compromise the therapist’s ability to remain detached/objective enough, so as to maintain a therapeutic stance:

“It feeds the sort of compassion and respect for the people we work with and decreases that “them and us” sense of; you know, it could never happen to me [...] at its best, that will mean, you know, good compassion, good respect, good collaborative working. I suppose at its worst, it means that you are conditioned to ‘idiot compassion’ you know. “I can’t be hard on you, I’ve got to mother you because that’s how I would like to be treated if the worst should happen and the axe falls on me, I want to be looked after, so I’d better look after you” (Dawn).

In order to manage the challenges faced by working with clients with chronic conditions, participants emphasised the importance of self-awareness. Sandra stated: “We need to be mindful of what our expectations are and what we expect of ourselves, how we behave in relation to disability or difference”. Dawn emphasised that one must “notice within oneself that actually there are certain illnesses that really get to you” and Clare reflected: “It’s very important to be aware of yourself”.

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Discussion

This study set out to ask: How do psychotherapists make sense of their clients’ longterm conditions? Analysis of the data developed two superordinate themes which described how participants anchored their understanding of their clients’ experiences by drawing similarities between themselves and their clients and distinctions with other client groups. These superordinate themes are discussed below.

No ‘them’ and ‘us’

The first superordinate theme describes how participants understood and made sense of their clients’ experiences by referring to the shared aspects of their experiences and emphasising the similarities between themselves and their clients, rather than their differences. In this way, even though participants had not personally experienced chronic illness, they were able to draw closer to their clients and their experiences by focusing on a shared vulnerability and by focussing on the person as a whole and on shared existential and embodied aspects of experience, rather than on the condition or illness itself. In other words, an awareness of human experiences like illness, suffering, mortality and embodiment enabled participants to focus on what made them similar to their clients rather than what set them apart (i.e. chronic condition). This focus on similarities enabled a loosening of the boundaries between “them” and “us”.

Manafi (2010) highlights that the relational stance stressed by counselling psychology entails the dissolution of artificial dichotomies imposed by empiricist/positivist frameworks, and situates clients and practitioners in a relational/intersubjective field where the individual becomes united with others and with the world. Consequently, the therapist as expert is “dethroned and now is located in the ‘realm of living’, where we all battle with life’s adversities” (Manafi, 2010, p. 29). The theme, No ‘them’ and ‘us’, describes such a dissolution of artificial dichotomies and situates practitioners alongside clients in facing existential adversities.
Kohut (1982) defines empathy as “feeling in the place of another”. It appears that the participants’ ability to identify with their clients’ position facilitated a sense of empathy and compassion and a more vivid connection to their clients’ experiences. Similarly, Frie (2012) explains that “emphasising basic similarities, a shared humanity, without trying to reduce difference into sameness, can create a familiarity with what does not correspond with the normative or ideal self” (p. 233) and thus facilitates an understanding of, and an approximation to, the other. It appears that although participants’ experiences were different to their clients’, participants were nonetheless able to relate to their clients’ experiences more closely and personally by focusing on their similarities.

The theme *No ‘them’ and ‘us’* is based on the notion of shared aspects of existence. This relates to Yalom’s (1980) ‘givens’ of existence, in particular the sub-theme *Focusing on a shared humanity* and its emphasis on suffering and mortality. Yalom (1980) describes the ‘givens’ of existence (death, isolation, freedom and meaninglessness) as “certain intrinsic properties that are [...] an inescapable part of the human being’s existence in the world” (Yalom, 1980). As such, these common intrinsic properties arguably provide a common ground for human experience and understanding. Indeed, it appears that they bridge the gap between clients and participants. However, Heidegger’s (2000) distinction between the ontic (i.e. plain facts of existence, e.g. death) and ontological (i.e. the personal meaning of existence and experiences relating to it) becomes important at this stage as the fact of collectively grappling with certain givens does not mean that each individual’s experience of these givens is the same. Indeed, this is what *Focus on the individual rather than the illness* addresses. It appears that while at one level participants draw their understanding of their clients from a broad sense of shared experience, they also focus on the unique experience of particular clients and the “two hundred different ways” (Sandra) in which they can experience their condition. Moreover, it could be argued that by focussing on the individual rather than the illness, participants are thereby able to focus on what is amenable to therapeutic change, rather than on what they cannot ‘fix’ (i.e. the body). “Hope is associated with a belief that goals are
somehow attainable” (Tong, Fredrickson, Chang, & Lim, 2010, p.1208). Focussing on the individual and on ‘attainable’ therapeutic goals may help participants to maintain hope by focussing on what they can ‘do’. (This idea is related to the sub-theme *Redefining therapeutic boundaries* discussed below).

*Focus on shared embodiment* describes another level of shared experience, that of having a body and relating with the world through it. Merleau-Ponty (1945, trans. 2000) describes how recognising one’s own and another’s embodiment enables the recognition/perception of similarities between one another (e.g. in terms of intention and ways of dealing with the world), thereby uniting the two in the experience of a shared phenomenon/existence. In other words, embodiment provides another anchor for shared experience as “we are all embodied” (Paula). Indeed, participants grounded their understanding of their clients’ experiences in their own sense of embodiment. The participants’ sense of “the groundedness of human experience in the physical body” (Sandra) may be partly inescapable given the context of their practice (i.e. working with clients with physical conditions). However, it may also be accounted for by participants’ personal frameworks of understanding, as several participants described how being able to work with the mind and body was “one of the main reasons I wanted to work in health” (Susan) and how it felt as if it had “a lot more integrity and [made] a lot more sense” (Paula).

The blurring of the boundary between “them” and “us” prevented the participants’ understanding of their clients from being dominated by the notion of ‘chronic illness’ and thereby enabled the conceptual and experiential gap between the therapists and their clients to be reduced, helping participants to make sense of their clients’ experiences. Participants also made reference to the implications of blurring these boundaries for practice and for the therapist. For instance, participants expressed how: existential issues and the impossibility of ‘fixing’ things were “on the table” (Sandra) and could be worked with “more actively-transparently” (Sandra); how therapy necessarily involved engaging with the mind and body; and how therapists had to face
their own mortality and vulnerability "far more" (Dawn) when working with this population.

**Redrawing boundaries**

The second superordinate theme developed from the data describes how participants made sense of their clients and of their therapeutic work together by distinguishing their clients from other client groups and redefining therapeutic possibilities, demands and challenges in light of such differences.

In the first instance, *Drawing the line between insiders and outsiders*, participants drew distinctions between their clients and other client groups. Interestingly, these distinctions were not centred on having a chronic condition or not, and what this might entail for the client or therapy, but on more pervasive characteristics like overall mental health, resilience and the ability to develop trust. Hegel (2003) describes how the ‘self’ is defined and constituted through defining the other and indeed it appears that part of developing an understanding of their clients and of their role as therapists involved defining other clients. Similarly, the process of developing a social identity by establishing in-groups and out-groups (i.e. ‘us’ vs. ‘them’) has been described by Tjafel and Turner (1979). By identifying with their clients (‘us’) and then drawing distinctions with other client groups (‘them’), participants described/constituted their sense of self and their social identity. In other words, whilst on the one hand the gap between ‘them and us’ was reduced because participants identified with their clients, the ‘other’ then became other client groups. Furthermore, by referring to the positive attributes of their clients to distinguish them from others [e.g. "competent, emotionally stable" (Susan)], the implication was that other clients don’t possess the same qualities. Consequently, an image of the ‘other’ as less ‘mentally strong’, resilient, or able to ‘run with things’ emerged. Thus, the in-group was implicitly positioned as superior to the out-group.
The process of identifying and describing the 'other' (usually in ways that portray the ingroup in a positive light) has been termed 'othering'. Othering has been defined as the "process of differentiation and demarcation, by which the line is drawn between 'us' and 'them'" (Lister, 2004, p.101). Kirschner (2012) describes othering as the process whereby:

"social groups affirm a common identity among their members by identifying "others" in relation to whom the in-group's (allegedly) shared features can be contrasted. Thus, "othering," in this sense, is the focus on, or delineation of, differences through which the in-group defines both its own characteristics and those of its others" (Kirschner, 2012, p.217).

Othering typically involves hierarchical relationships, with the self being positioned as superior to the other (Kirschner, 2012) and has been described extensively by postcolonial and feminist theorists (e.g. de Beauvoir, 1989; Said, 1978). While in psychology, othering is a concept usually discussed within discourse analysis, it is a concept which contributes towards understanding how participants in this study made sense of their clients' experiences and their therapeutic work. That is, by defining their own and their clients' characteristics in relation to 'others' and subsequently defining their therapeutic work and interpreting their experiences in light of these differences.

Redefining therapeutic possibilities, refers to how the differences between their clients and 'others' described by participants were viewed as positively influencing the nature of therapy and the therapeutic relationship and as being personally meaningful and relevant to the participants as therapists. Participants described the 'excitement' and 'gratification' they experienced when working with this client group as opposed to the "frustration" (Paula) and "deferred gratification" (Dawn) of working with other client groups. Their sense of being able to "do a great deal very swiftly" (Paula) and "at a good pace" (Dawn) was linked to their sense of achievement and satisfaction as therapists. Rupert, Miller, Hartman, and Bryan (2012) suggest that "it is important to have cognitive strategies for maintaining a healthy perspective on one's work" and
that “learning to savour the rewarding aspects of one’s work” is particularly helpful in facilitating a high level of career satisfaction (p.501). Indeed, participants’ emphasis on being able to ‘do’ more as therapists seemed meaningful to them, as it functioned as a source of encouragement and heightened their motivation and sense of agency. Promoting ‘growth and change’ has been identified as one of the most satisfying aspects of therapeutic work (Farber & Heifetz, 1981) and focusing on ways in which one has promoted growth has been identified as a protective factor for psychotherapists, which contributes towards better coping and job satisfaction (Kramen-Kahn & Hansen, 1998). Perhaps the participants’ focus on being able to achieve more therapeutic results with their clients functioned as a protective factor and contributed towards making their work more satisfying. (Further research into how psychotherapists working with clients with chronic conditions cope with the stress of their work and avoid ‘burnout’ would be useful).

There seemed to be a value for participants in focusing on helping psychologically, although they could not help physically. It could be argued that being able to ‘do more’ with this client group somehow helped participants to balance the sense of hopelessness/helplessness of not being able to ‘fix’ their clients physically. This enabled participants to ‘be there’ with their clients while holding on to a sense of potential and possibilities and to derive greater satisfaction from their work. Clients’ differences were also portrayed as enabling them to develop “the trust that enables you to do something really exciting” (Dawn), and to take action e.g. “pick up and run with stuff” (Dawn), or progress in ways which facilitated therapeutic development. Tong et al. (2010) have found that “hopeful people tend to think that desired goals are attainable even if personal resources are exhausted” (p. 1213). Perhaps by combining resources with their ‘mentally stronger’ clients and by focusing on the ‘more collaborative’ work they could do with clients and highlighting the clients’ own potential and agency, participants could maintain a more hopeful outlook for their clients.
Finally, *Different challenges and demands*, pertains to participants’ understanding of the additional complexity faced by clients and by therapists when clients experienced both physical and mental health difficulties. Participants felt that taking both aspects into account could make the work more complicated. Additionally, participants felt that exposure to one’s own vulnerability was challenging and that the sense of being unprotected from illness blurred the boundary between client and therapist, which could facilitate a more compassionate, respectful and collaborative relationship. However, this could also compromise therapists’ ability to remain detached/objective enough, thereby interfering with the therapy. Frie (2012) emphasises the importance of empathy and compassion in order to facilitate therapists’ engagement with their patients (i.e. the Other) and to avoid the othering of difference. He argues that compassion for the other enables the exploration of the other’s experience “in ways that a dispassionate stance may not” and which result in the attenuation of othering (p. 233). Indeed, being able to put themselves in their clients’ position increased the therapists’ ability to connect more vividly with their clients’ experience and to relate to them in therapeutic ways. However, therapists must be mindful that over-identifying with clients’ vulnerability may influence the therapist’s view of clients as responsible and accountable and affect their ability to question their clients’ behaviour.

**Limitations**

In IPA, “the contextual and cultural ground against which data are generated” (Reid et al., 2005, p. 20) is of great importance. Therefore, a mention of the impact of the context in which the participants’ experience was embedded must also be considered. Frie (2012) points out that “recognising difference and responding to otherness occurs in a social and societal context” (p. 232). The system within which the participants practice classifies clients by “presenting problem”, in order to allocate them to different services, and therefore the context in which participants work may be the “designated otherer” (Kirschner, 2012, p.219). Indeed, the current NHS system requires the categorisation of clients according to physical or mental difficulties, in order to access different psychological services. Therefore, the way service provision
is currently structured remains very dualistic. The rationale is to provide specialised services to clients. However, it also creates a context in which othering is tacitly enacted as well as explicitly stated. This has potential implications for how therapists understand their clients and their work and for the subjectivity of clients who are clustered according to whether their 'primary' difficulties are deemed physical or mental health-related. While categories are useful in order to create some order in terms of inclusion/exclusion, Kirschner (2012) stresses that if institutions did not require the framing of different groups or identities in such inflexible/homogenous terms, then othering could be attenuated "because we wouldn't be so obsessed about our boundaries and what our identities should, and shouldn't, contain" (p. 222). This raises questions regarding the ways in which working in different contexts where 'othering' is attenuated, directed at different 'subjects', or of a different nature, would affect how practitioners conceptualise and make sense of their clients' experiences and of their roles as therapists. It also questions the impact of a dualistically structured system on clients' understandings of their experiences. Further research could shed some light on these considerations.

Conclusions

Dealing with chronic illness in a psychotherapeutic context is a process that requires psychotherapists' understanding of their clients' experiences and of their therapeutic work together. This study adopted a qualitative methodology to explore in depth how participants constructed their understanding of their clients' experiences and of their therapeutic work together and elucidated some psychological and therapeutic processes relevant to practitioners working with people with long-term health conditions.
Personal Reflections

I began this research with many expectations about what clients with chronic conditions would bring to therapy, what therapeutic practice with this client group might entail and what experiences would be described by therapists in this speciality. I was excited to be able to talk with seasoned practitioners and hear their insights into these issues. To my surprise, my assumptions were completely challenged by participants’ accounts. For instance, one of the reasons why I wanted to explore practitioner’s experiences stemmed from my own assumptions about hopelessness/helplessness. I wanted to understand how therapists and clients managed when dealing with conditions that would not go away. I imagined that working with a population that could not be ‘fixed’ or cured, and that might even deteriorate, would be really difficult. How did practitioners face death and illness day after day and manage to do their work without becoming discouraged? I also wondered how they could help people who ‘had no hope of getting better’ not to sink into depression/hopelessness and to live their lives in fulfilling ways.

Similarly, when I asked participants to compare working with clients with chronic illness and other clients, I expected responses about hope or hopelessness which stemmed from bodies that couldn’t be cured, about how it affected practitioners to work with people they could not ‘fix’. I was very surprised to hear stories of how strong clients were and how rewarding they found their work together. This made me aware of my own assumption that mental health difficulties were somehow more ‘fixable’, less permanent and more amenable to therapeutic progress than physical difficulties. This has been an important point of reflection for me this year, which has generated more questions than answers.

This research has triggered a really valuable period of growth for me as a person and as a therapist. In particular, it helped me to become aware of and reflect on my own distancing and ‘othering’. I realised that I was holding dichotomous views about myself, as a person and as a therapist, and people with chronic conditions. I had been
focusing on ‘their’ mortality and ‘their’ vulnerability and ‘their’ helplessness and the
limitations imposed by ‘their’ bodies and I was conveniently forgetting all about my
own. Without realising it, I had been ‘othering’ people with chronic illnesses and
viewing their difficulties as alien to myself. Overcoming this ‘illusion’ has been one of
the hardest and yet most life-affirming lessons I have learned so far. As my placement
has been with people with chronic conditions, it has also been a valuable lesson for
my practice, helping me to be more aware of my clients’ and my own fragility, and of
the importance for one’s wellbeing of questioning assumptions about the implications
of being ill. Indeed, some people with chronic conditions live fuller lives than people
who are ‘unimpaired’. Where do the restrictions lie? In the individual, in the
condition, in society...?

This research was also a valuable lesson in the power of qualitative research and of
bracketing one’s assumptions. In particular, I remember a debate with my supervisor
about including a question concerning hope in my interview schedule. Her position
was that I could not ask about hope because that would elicit hope-related responses
regardless of whether hope was actually part of the participant’s meaning-making
process or not. Instead, I should see whether hope emerged within their responses.
This helped me to understand that asking directly about hope assumed: firstly, that
hope played a part in my participants’ experiences; secondly, that ‘hope’ was a thing
out there that existed and could be investigated; and thirdly, that participants would
experience and describe ‘hope’ in similar ways, rather than acknowledging the
multiplicity of interpretations of this concept and its application to their lives.
Although I was initially frustrated about not being able to ask specifically about hope
unless it ‘emerged from the data’, this was a powerful learning point because it made
me consider how different the data would have been had I done so, illustrating the
importance of the researcher’s assumptions, interests, questions etc. in what is elicited
from participants (and clients in therapy!) and how responses are interpreted.
Additionally, it allowed the participants to share aspects of their experiences which I
would never have expected and which made this research so much more enriching for
me. It helped to challenge my assumptions about myself, about clients and friends
with chronic conditions, and about the thinking/philosophy that sustains some practitioners who work with people with chronic conditions.

Finally, I must acknowledge that my understanding of the participants' responses is influenced by my own context and being on placement with people with chronic conditions. I began this research shortly after starting my placement and I believe that I approached it with a more naïve and fresh outlook than I would have at a later stage. However, I am aware that my perspective and theoretical and clinical understanding have evolved over the course of the year and have been influenced by my participants and fellow practitioners. My personal experience will no doubt have affected what stood out for me and how I understood my participants' accounts. I really struggled when writing about 'othering', as I felt I was somehow betraying my participants and I feared causing friction. I took comfort in Kirschner’s (2012) ‘normalising’ description of othering as both “problematic and indispensable” and as something we all do (p. 217). Taylor (2011) outlines how conducting research from an ‘insider’ position can offer a range of significant advantages and disadvantages and that one must be mindful not to “presume that as an insider, one necessarily offers an absolute or correct way of seeing and/or reading the culture under investigation” (p. 6). I have tried to stay as close to participants’ accounts as possible and not to let my own ‘insider’ assumptions and ‘loyalties’ cloud my understanding of the participants’ experiences or drive my interpretations. However, my unique positioning will inevitably have influenced the outcome interpretations.
References


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APPENDIX A - SAMPLE PARTICIPANT INFORMATION SHEET

Postgraduate Research Study: How do psychotherapists/psychologists make sense of their client's chronic illnesses/conditions?

This information sheet will provide you with information explaining the purpose of the research and why you have been invited to participate in this study. Below you will also find information regarding what your participation in the study will involve and contact information in case you have any questions or would like more information. Please take time to read the following information carefully and to decide whether or not you wish to take part in the study. Thank you for reading this.

What is the purpose of the study?

The aim of this study is to explore how psychotherapists/psychologists make sense of their client's chronic illnesses/conditions. A better understanding of chronic illness from the perspective of psychotherapists/psychologists could provide new and richer understandings of the perspectives that inform psychotherapists/psychologists working with clients with chronic illnesses/conditions. This could help to develop new ways of understanding and dealing with illness and inform new psychotherapists/psychologists about the psychological treatment of people with chronic illnesses/conditions.

Why have I been chosen?

You have been invited to participate in this study because your experiences, thoughts, and feelings can offer a unique and personal perspective on what it is like to work with this client group.

What will participation involve?

The interview can be carried out at a location which is convenient and comfortable for you. The interview will be based around a semi-structured interview which will take approximately 60 minutes. If you would be willing, a follow-up interview to clarify or expand on certain points would be carried out at your convenience before March 2013.

This interview is intended as an opportunity for you to describe your work with clients with chronic illnesses/conditions. The interview will be recorded, transcribed into text form, and stored digitally. The transcription may be carried out by the researcher or a
transcription service bound by a confidentiality agreement. In order to ensure confidentiality, the information will be securely stored on a password protected computer, and your name and any other identifying information will be removed so that you cannot be recognised by the information provided. In addition, you will be offered the chance to review your interview transcript and to remove any information which may violate your confidentiality. Any forms containing personal information will be stored in a locked unit which only the research supervisor will have access to.

As part of the presentation of results, your own words may be quoted. However, this will be anonymised, so that you cannot be identified from what you said. In line with the Code of Good Research Practice (http://www2.surrey.ac.uk/fahs/staffandstudents/ethicalprocedures/briefing/ethics_documents_list.htm), all the data will be securely stored for a period of time and will then be destroyed.

Please note that your participation is voluntary. You can decide not to answer questions that you don’t wish to or to stop the interview at any point. You can also decide to withdraw from the study, in which case the information you provided will be removed and destroyed.

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Additionally, you will be provided with the interview questions before the interview takes place so that you will have an idea of what to expect. Should you wish, a copy of the study could be provided to you once it is complete.

This study has been given a favourable opinion by the University of Surrey.

You can contact the University of Surrey using the details below for further advice and information:

**Supervisor's name:** Dr. Dora Brown  
**Department address:**  
Department of Psychology  
Faculty of Arts and Human Sciences  
AD Building  
University of Surrey  
Guildford  
Surrey  
GU2 7XH  
UK  
**Email:** dora.brown@surrey.ac.uk  
**Phone:** 01483 68 3979

**Researcher:** Isabelle Crossley  
**Department address:**
Thank you for participating in this study!
• I, the undersigned voluntarily agree to take part in the study on *client's chronic illnesses/conditions*.

• I have read and understood the information sheet provided. I have been given a full explanation by the investigator of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

• I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the results of the study, on the understanding that my anonymity is preserved.

• I understand that I am free to withdraw from the study at any time up to the point at which data analysis begins without needing to justify my decision and without prejudice.

• I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

• Please tick here if you do not wish to be contacted for a follow-up interview  □

Name of volunteer (BLOCK CAPITALS) ....................................
Signed ..........................................................................................................................
Date .............................................................................................................................

Name of researcher/ person taking consent (BLOCK CAPITALS) ......................
Signed ..........................................................................................................................
Date .............................................................................................................................

Participant Number (you will need this if you want to withdraw your results at a later date): ___
APPENDIX C - SAMPLE DEBRIEF FORM

Participant Debrief Form: How do psychotherapists/psychologists make sense of their client’s chronic illnesses/conditions?

Participant Number (you will need this if you want to withdraw from the study at a later date): __

The general aim of this study is to explore how psychotherapists/psychologists make sense of their client’s chronic illnesses/conditions. The objective of the research is to develop a better understanding of chronic illness from the perspective of psychotherapists/psychologists, which could provide new and richer understandings of the perspectives that inform psychotherapists/psychologists working with clients with chronic illnesses/conditions. Additionally, this could help to develop new ways of understanding and dealing with chronic illnesses/conditions psychotherapeutically and to inform new psychotherapists/psychologists about the psychological treatment of people with chronic illnesses/conditions.

Psychotherapists/psychologists working with people with chronic illnesses and conditions have been invited to participate in this study because their experiences, thoughts, and feelings can offer a unique and personal perspective on what it is like to work with this client group.

If you would like further advice and information please contact the University of Surrey using the contact details below:

Supervisor’s name: Dr. Dora Brown
Department address:
Department of Psychology, Faculty of Arts and Human Sciences, AD Building, University of Surrey, Guildford, Surrey, GU2 7XH, UK
Email: dora.brown@surrey.ac.uk
Phone: 01483 68 3979

Researcher: Isabelle Crossley
Department address:
Department of Psychology, Faculty of Arts and Human Sciences, AD Building, University of Surrey, Guildford, Surrey, GU2 7XH, UK
Email: ic00027@surrey.ac.uk
Phone: 01483 68 3979

Thank you for participating in this study!
APPENDIX D- DEMOGRAPHIC QUESTIONNAIRE

Age: ______
Gender (please circle): Male / Female
Race/Ethnicity: ______
What is your marital status? (please circle): Single / Married / Separated / Divorced / Widowed / Civil partnership/ Other (please specify) ______
How many years have you been working as a clinician/therapist? ______
How many years have you been working with people with long-term/ chronic illnesses/ conditions?

_______
1. I wonder if you would mind giving me your understanding of "chronic illness/condition"?
   (Prompts depending on answer).

2. What do you think it is like to have a chronic illness/condition?
   (Prompts depending on answer).

3. I know you work with clients with chronic illnesses/conditions. What is it like to work with them?
   (Prompts depending on answer).

4. Could you compare clients with chronic illnesses/conditions with clients who don’t have a chronic illness/condition?
   (Prompts depending on answer).

5. What is the future like for people with chronic illnesses/conditions?
   (Prompts depending on answer).
I: Ok, cool. Ok. So I wonder if you would mind telling me what your idea of chronic illness is?

P2: Chronic illness... It's not really a term I use very much, but I suppose I would see it as one that affects people quite a lot of the time and it may wax and wane a bit but it doesn't completely go away and is not likely to go away in the foreseeable future. There isn't a treatment that will take away all the symptoms that the person can have.

I: When you say that it's not a term you use a lot, is there a reason for that?

P2: I think it's horrid to say "chronic". I think it depresses people and it's just not a way I talk about things, so I tend to talk about "long-term" conditions, rather than "chronic". "Chronic" just feels feeble (Laughs). And passive.

I: And how is "long-term" different then?

P2: Well it sets the scene. It's realistic, about "This isn't going to go away", but it doesn't have that valence, that sense in which somehow you are "chronic". You're chronic and - you know about the hospitals and the homes for incurables and there was a kind of way in which once you were chronic or incurable, that was it. You just sat there in your bed and the people gave you painkillers or patted you on the head but you weren't responsible for trying to make the best of your life or even anything of your life so I suppose "long-term" conditions feel slightly - leaves more wriggle room for saying this is still a life and it's a life that can be worth having.

I: That's really interesting. Could you tell me more about that?

P2: I think if I talk about it in stage terms, most of us grow up with a sense of what it is to have flu or other short term illnesses that mean that we, you know, go to bed for a day or two or a week or two, take painkillers or antibiotics or something and just generally let ourselves off the hook and concentrate on getting better. When you develop a longer term or more serious condition, what can then happen is you get very fixed on managing the condition in that same way, that somehow until you sorted it, got rid of it, got a treatment that gets it under control, your life is kind of on hold and everything you do is geared around the next hospital test or doctor's appointment or trial or treatment or searching the internet to see what else might be available that's not being offered to you, or... You become very illness-centric. And I think our work as psychotherapists is to move people forward from that through a process of mourning the life they won't have, while staying in touch with their values and what was really important to them about the way they wanted to live life and find a way of translating that absence of values and purpose into the life that they will have with their condition.
I: Great!

P2: Ok? I don't know whether that sounds very... I feel I'm giving a lecture (Laughs.)

I: No, it's really interesting. Yes, I guess that you've touched on it a bit, but I'm wondering what you think that it's like to have a chronic illness or condition, longterm illness or condition?

P2: What it's like? Are you aiming for physical conditions or mental conditions as well?

I: I guess in this case physical although I guess it can go hand in hand. What makes more sense for you, or what do you...? Or even maybe if you are seeing differences in both it would be interesting to see how you view that.

P2: Can you just repeat the question, again? 'Cause I think I got lost.

I: Yes. It is: "What do you think it's like to have a chronic illness or condition?"

P2: I think there's as many ways it can be as there are people who can have it, essentially. I think long-term conditions often leave people very angry, feeling they've been robbed. They have a tendency to hit at people's sense of self-esteem, you know, our sense of selves as capable, able to paddle our own canoes, manage everything independently and without needing much help from other people tend to be hit quite hard and somehow one's sense of being able to manage stuff independently, for many people, is tied up quite closely with their sense of being a valuable human being. They don't have much sense of value that isn't expressed in terms of "I can do this or that or whatever." And so I think people often feel quite overwhelmed by illness, very frightened about the future and what it might hold, lots of long-term conditions are kind of progressive and they often feel quite uncertain, because, you know, in the short term, they start to feel quite unsure about things like: "Well, will I be well enough to do whatever it is I want to plan for next Thursday?", so it can be very tempting to kind of put things off rather than take the risk that you plan something, and then it's a bad day and you can't do it, and then in the longer term there's that sense: "If I don't do it now, I might have a relapse or the illness may progress and I might not be able to do things. I don't know whether I'll be able to do things in a year's time or three years' time or two years' time and that brings all sorts of kind of extra stuff around, you know: "Do I save money now or do I splurge it? Do I stop wasting time on loads of friends and just concentrate on one or two key people? It kind of unsettles everything that one kind of thought in terms of, you know, I'm sure you're the same as me, you know: "I don't need to do x this year because I can get around to it. I'll just get this next exam or I'll read this next book or I'll, you know, do this next job, you know, one has a sense of a whole bunch of things one's going to do when one's retired (laughs) and then to have that suddenly taken away in terms of well
maybe there won’t be a long retirement or a healthy retirement in which one will have energy and resources to go ahead and do stuff, and then on top of that often, you know, you can’t work and so you’re not earning money. You’re on benefits and money can be very short and expenses go up if you can’t drive or you can’t get about even... I might need that question again? I don’t know if I answered it.

I: What do you think it’s like to have a chronic illness or condition?

P2: Yes, I think most people feel really boxed in by all those things I mentioned and by the imponderableness of it, you know, if you have multiple sclerosis, you may be dead within three or four years or you may have thirty years of low-level chronic disability and the doctors won’t know. If you have a brain tumour, the chances are you’ll be dead in five years, plus or minus one or two. But some people make it to 20 or 25, some don’t make it till Christmas. Nobody ever gives you those kinds of answers. They can’t give you those kinds of answers ‘cause we’re always wrong as often as we’re right. I think it’s really hard to live with that level of uncertainty. Everyone lives with the unknown: you know, I could go under a bus on my way home this evening, but I don’t think about it. Once you’ve got a long-term condition, it’s always in your mind.

I: And so what’s it like for you to work with people in these conditions and these circumstances?

P2: Well I like it (laughs.) You know I like it. What’s it like? I think it’s exciting. That’s possibly because of ... Well, I suppose I have a couple of views: one is that death and illness don’t frighten me nearly as much as going mad. That always frightened me, so there is a sense in which this is much easier than working with bipolar disorder or schizophrenia or psychosis, you know or... not dementia, actually. I’m cool with dementia, which is, I think, quite interesting really. But that true kind of losing touch with reality, being plagued in your very soul by voices that torment you or moods that simply do not respond to any behaviour or things that you do. I find the pain of working with people who are struggling with that sense of, you know, total vulnerability and out-of-controlness much harder than working with people in the, you know, very difficult stages of their illness or towards the end of life. I don’t know... I think partly probably because (?) kind of fearing my own madness and loss of control but partly, I think, because most people with long-term conditions... the work that we do, because mentally they are stronger, quite small interventions go a really long way, so it’s really exciting to see how a small piece of work with someone they pick up and run with ... and they do things we would never have predicted or exactly been aiming for, but nevertheless it works for them and so there’s... I suppose, yes, there is that, the way that people with longterm conditions pick up and run with stuff is really inspiring (laughs) so I love that and that sounds really weird, when you’re talking about people with disabilities, you don’t get up and run anyway, because they’re in wheelchairs or whatever, but they... I don’t know, there is something really inspiring about that and I also think it’s much easier to work alongside and in collaboration with

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people with long-term conditions than it is... Most of the work in mental practise is about trying to build a relationship. You can work for years to build a relationship to get to a place where you can start to work with someone and people with long-term conditions, you know, within a session sometimes, certainly within a couple of sessions you’re off and at a very good place in which the trust that enables you to start doing something really quite exciting, so I never was much into deferred gratification (Laughs). And I suppose there’s something actually also about the... Although we often have a long-term relationship with people, so we see them repeatedly at different stages of their illness, we rarely work with people long-term and we much more often do a chunk of work and then we know that we’ll meet again at some point, but, you know, we don’t see it as our job to kind of hound people, and it’s much easier to be, you know, to be saying to people, you know: “This is when we’ll need to meet again,” and feel confident that they will be able to kind of recognise that and come back, whereas again someone with schizophrenia, you kind of have to do the: “Well, we’d better clap eyes on you in three months’ time just in case you’re going off and you don’t know too sure. You know, people with long-term conditions, they get it. They know when they need a bit more help and when it’s going to be important to make something happen. Am I doing ok?

I: Yea, perfect! Thank you. I guess you’ve kind of gone into that... I wonder if you would want to add anything. The next question is: “Could you compare clients with chronic illnesses or conditions and clients who don’t have chronic illnesses or conditions?”

P2: I don’t know! I don’t see many people who don’t have chronic conditions. Only occasionally I see people who have had something bad happen to them. They’ve been cruising along perfectly happily and then, I don’t know, they’ve had an accident, or an operation’s gone wrong, or they’ve had an acute illness and it’s taking a bit to get back on track, but by and large, I don’t see people who don’t have a chronic condition, so I’m struggling to think what the difference would be with... in client terms, I mean I suppose the difference would be that primarily with those people who don’t have a chronic condition, you’re dealing with either kind of post-trauma kind of things or adjustment things or you may be dealing with... People often have a sense of having lost their luck, if they’ve had an accident or an illness that suddenly creeps up on them, that somehow all their life they’ve, you know, got away with things, and then they have a sense of being more vulnerable than they really are, but assuming that, you know, the worst is going to happen. It’s going to happen on every single thing that happens to them and that they’re not going to see it coming or they’re not going to be able to deal with it or it’s going to be really terrible, so people can get into a kind of generalised anxiety, health anxiety sort of state, so I suppose there are some of those around. And I suppose, as I say, often people have fairly traumatic memories of an acute thing that’s happened to them and we sometimes see I don’t know: women who’ve had traumatic deliveries or people who’ve had accidents and traumatic experiences in A&E or intensive care, so although they are physically better, actually they’re still having flashbacks or whatever to whatever happened to them. You don’t
see them very often, to be honest, 'cause really they should go to IAPT. IAPT don't
tend to want them so they do find their way through sometimes. But we don't see
them very often, so it's kind of, it's not something I know much about really. You said:
“The difference between that and the long term conditions” was the long-term
condition does tend to be, as I said before, very much more the... that whole process
of being very clear about the life you were planning to have, mourning that and then,
kind of beginning to get that sense of “who am I and how is that going to play out in
the life I will have?” But you do have to get that, you’ve got to get through that sort
of, you know, that transition curve, the Kubler-Ross curve, the kind of getting through
the kind of crossness and that it’s there and coming up the other side into
purposefulness again, I think, which I don’t think you do have to do with the more
acute illnesses. In the more acute illnesses, ok, it’s unsettled you so you kind of have
to get to grips with the fact that you now know that terrible things can happen and
they can happen to you, but on the other hand you got away with it. Your legs and
arms still work, you know, you can still see and do what you need to do, so you don’t
have to do that kind of adjustment bit.

I: Ok. Again, it might be a bit of a repetitive question, but it is: “What is the future like
for people with chronic or long-term conditions?”

P2: Oooh! (pause). I suppose... I suppose... What is the future like? I’m struggling to
come up with a generalised answer, really. I suppose like for anyone it’s what they
make it. But in order to make it a good one, usually the biggest challenge is this: how
do they develop a system, how do they create relationships that are going to be
sustainable? We need some sort of exchange in which, you know, the physical needs
that they will have to have other people serve for them can somehow be repaid, and so
there’s a sort of whole system aspect to managing a long-term illness that is often a
challenge and that’s kind of at many levels: you know, there’s a kind of society/political
level. In January the rules have changed. They tend to change every single
year. They never change for the better, so, you know, to live by your... You know,
you’ve just been given disability living allowance now, do you go ahead and risk
buying the car and risk that you won’t be part of the cohort that continues to get
D.L.A. and you might not be able to pay for the lease for the 3 years that you signed
up for. Or do you wait until January, only to discover that people who have already
signed up are ok for the duration of their lease and, you know, so there’s that kind of
political... and I mean, I suppose I empathise with the frustration because I think ... I
get so enraged with the Today programme and the news and the television where
politicians mouth off about... I can kind of understand the problem we’ve got with
people who don’t bother to work, but people with long-term conditions get caught up
in that net, particularly people who maybe have 2 or 3 conditions which kind of act
together. You know, they have pain and they have something else and they have
something else. You know, it’s relatively ok if you have MS and you’ve gone beyond
a certain level. People kind of accept that you can’t walk. You need help. But often
people can end up with 2 or 3 kind of slightly less... I’ve got a lady at the moment
who’s, you know, kind of got a completely cronked knee, but she’s also got ME and
she does tend to have epileptic fits from time to time. Now, you take all those
conditions together, you know, and you say to yourself: “Well, ok, the cronked knee,
she can’t do anything that’s walking around but she could be an admin person, but
actually the chronic fatigue means that she probably couldn’t sit and do that because
her arms would get too tired and the epilepsy, you know, would potentially do her out
of certain other operating machinery type jobs and even, you know, quite a few public
facing jobs as well. So I mean, just think to yourself, well none of those conditions
is... you know, if you only had one of them it would be fine, but you get three of them
together, so that can be really difficult. So there’s that sort of political/society - people
who want to make a... make themselves popular by being hard on people but then
actually don’t think of the implications of what it’s like. And then there’s the kind of
more local level of, you know, friends will rally round for a bit, but after a bit, making
sure that, you know, you’re included in activities becomes really hard work and you
do get forgotten about, and, you know, you may have thought that you had 20 or 30
friends maybe a crowd of people you knew and liked and liked you and included you
and you did things with. You know, you’d be lucky if you’ve still got one or two
friends who regularly come and see you, who are willing to go the extra mile to
include you in theatre trips, or, you know, if you go out for a meal are making sure
that the place is wheelchair-friendly or, you know, or even be willing to go out of their
way to pick you up to take you somewhere if everybody’s going off as opposed to
thinking: “Oh, well, we’ll all meet up there in the car park.” Er, no! You won’t! You’ll
get left out. So there’s that. That bit I think is really difficult and then the kind of... the
way in which the family has to kind of rearrange themselves. Anyway, I think I’m
running out of steam (laughs).

I: No, that’s great. Is there anything that you feel that is important that I haven’t asked
or that you would want to add about working with people with long-term conditions?

P2: I suppose - this is just as kind of someone who does training and supervision, I
think working with long-term conditions is challenging to many therapists. It’s quite -
my sense, it’s quite... In mental health, trainees often have quite a secure sense that
they would never go mad in the way that their patients are mad or in learning
disabilities, you know, they kind of know they missed the boat on that and it would
never happen to them, whereas most of the conditions that we work with here are
things that you could discover you’ve got tomorrow. You could have cancer, you
could have heart problems, you could turn out to have Parkinson’s disease, or motor
neurone disease, or MS, or arthritis. In fact, the probability is that, you know, within
the range of things that we see here, you will, before your time is done, have at least
one of those conditions and I suppose what that means is that one has to kind of take a
slightly different... One has to kind of notice within oneself that actually there are
certain illnesses that really get to you. I mean mine is motor neurone disease. If there’s
one thing I really, really do not think I could ever manage and would be off to
Switzerland very, very smartly if it were diagnosed, it’s motor neurone disease. I just
hate, you know, what that does to people. There are one or two other things I might
consider it, depending, but MND I would probably, you know, that would be it. I
would not live with that and I think one has to face that sense far more as a therapist, that actually the likelihood is that one of these conditions will get us, sooner or later.

I: What effect do you think that has?

P2: Well, I mean if I think about it in terms of trainees, people either love it or hate it, and I think that’s kind of around - you know, some people actually almost kind of think: “Well the more I work in this, the more likely I am to have kind of practised beforehand and (laughs) now I’m kind of ready to cope”, or, you know, get inspired by the way that people handle things and that gives them some kind of almost comfort that actually these things are survivable. Or they ricochet off it and go back into mental health (Laughs). And think: “Thank goodness that was only a placement. I don’t have to do it forever.” I think in terms of people who come into a specialty... What does it do to us? (pause) I kind of like to think that it actually... it feeds the sort of compassion and respect for the people we work with and decreases that “them and us” sense of, you know, it could never happen to me, I would always avoid that, you know, that’s a hole I would never fall in, which, I have to say, I always found really difficult when working in mental health but apart from, you know, I can think of some exceptional therapists who aren’t like that at all, or staff who are not like that at all, but too many people did have that sense of: “They could if they wanted to” or “They should pull themselves together”, or “Why can’t they?” and a real “them and us” sense which I don’t think I find quite so much in health, either in psychotherapists, or indeed, you know, if I think about specialist nurses, and a lot of the doctors we work with, far more realism that, you know, I could wake up and find I’ve got a brain tumour tomorrow or whatever. I hope I won’t, but it could happen, and I don’t know. I know hospitals are unkind to people who take overdoses or smoke or are fat or whatever but with a lot of these long-term conditions, I think, there’s far more of a sense that actually, you know, you didn’t bring it on yourself and it could happen to me, and so on the one hand, at its best, that will mean, you know, good compassion, good respect, good collaborative working. I suppose at its worst, it means that you are conditioned to idiot compassion, you know, “I can’t be hard on you, I’ve got to mother you because that’s how I would like to be treated if the worst should happen and the axe falls on me, I want to be looked after, so I’d better look after you”. But you don’t find that very often. I think, you know, more often than not, you do get that good collaborative working and I think the patients hold you to it more as well. I don’t think they’re as willing to be told that they don’t know what they want (Laughs) - those mental health patients you know that what they want is a symptom of their illness (Laughs). I dunno.

I: I guess I’m getting a sense that not only are the client groups different but the therapists that work with each client group are kind of different. Is that something that you... Is that how you see it also? You said that – you were saying that the trainees will ricochet and say: “I’m getting out of here. I’m going back to that.” There’s a kind of difference in personalities, character, I don’t know...?
P2: I’m not sure if it’s personality or character, either. Maybe previous experience or patterns. I don’t know whether it’s personality or character. I think it would be very interesting to do a kind of personality assessment of really, really, really, good, you know, supershrink therapists in different settings, because I suspect that although they might choose different things - might grab them, our best folks will have far more in common regardless of their specialty. They will have found something that really works for them, excites them, working with people that they can feel respectful for and collaborate with and you know, the fact that I can’t do it in mental health is fine because there are other people who are really good at that and, you know, really get off on working with... You know, (name) is an excellent therapist. I couldn’t do what she does. But I’m sure she, you know, she does it really well with the early interventions team but equally, you know, I don’t think she could do what I do. So I think it would be a very interesting thing to look at the personality structure or whatever and I suspect that good therapists have a personality structure and it doesn’t depend on... You know, what grabs you about a particular specialty probably is more to do with life experience or... I don’t know. I don’t think I would have ever thought about health. I mean I certainly signed up to be a clinical psychologist assuming that I would work in mental health. At the time I did, nobody worked in physical health and I’m trying to remember how I first discovered I could do it. And I think it was partly because I did neuropsychology, so I met a lot of people with neurological conditions and although the job was only about assessing them, because in those days that’s all that we did, you know, we’re talking about mid-seventies, I kind of got the idea that there was stuff to ‘therap’. And then I managed to get some money and... We got some money to do some research on providing therapy in primary care and the GP’s that we worked with on that project said: “Well, would you mind seeing some of our patients that don’t really have psychiatric illnesses?” Because they happen to be quite interested in people with obesity and some of the long-term conditions like the neurological conditions and they were quite interested in patients who had heart problems as well and blood pressure problems, and so we started working with them as part of that project, so I kind of... But at that stage, I think people were only just beginning to think: “Well, hey, CBT might have something to offer.” People who are physically ill - which isn’t about curing their heart disease, but may be about managing the fact that, you know, a heart goes (fluttering noise) is very anxiety provoking and might make you start avoiding doing stuff and spiralling down but if you could actually get over the anxiety you could live a more rewarding life, so I don’t know that... I don’t know how people make the decision now, that’s probably more one for you to answer (laughs) but, you know, when I came into it, there was absolutely no assumption. It was all a case of kind of: “Well, let’s give it a go and see what we can do.” There weren’t the protocols. We just had a go (Laughs). And if it worked, it worked and you were kind of chuffed with it and did it again.

I: Wow.

P2: I don’t think you are allowed to work like that anymore. You’ve got to have a protocol or a theory or something, but we just gave it a go. So, I don’t know if that answers the question.
I: Great. Thank you. Yup. I have no more questions, but anything else that …

P2: Anything else?… Just remind me of your research topic again?

I: It’s: “Therapists’ experiences of working with people with chronic - long-term conditions.”

P2: (Pause) I don’t think I’ve got anything else I can think of.

I: No? Great.

P2: I hope that’s been useful.

I: Thank you so much.
APPENDIX G – SUPERORDINATE THEMES AND SUB-THEMES

No “them” and “us”
Focus on shared vulnerability to illness: ‘One of these conditions will get us, sooner or later’.

• “It could happen to me” (Dawn) 388
• “I could wake up and find out I have a brain tumour or whatever” (Dawn) 125
• “Most of the conditions we work with are things you could discover you’ve got tomorrow” (Dawn) 341-342
• “You could have cancer, you could have heart problems, you could turn out to have Parkinson’s disease, or motor neurone disease, or MS, or arthritis” (Dawn) 342-344
• “The probability is that [...] you will before your time is done, have at least one of these conditions” (Dawn) 345-346
• “The likelihood is that one of these conditions will get us sooner or later” (Dawn) 356-357
• “It could be, you know, any one of us” (Susan) 323
• “It’s not a me and them kind of thing” (Susan) 325
• “It could come along any moment and we could have a pain, a break, a gastric problem” (Susan) 327-329
• “Anybody can get a chronic illness. Sometimes it’s lifestyle-related sometimes not” (Paula) 208-209

Focus on shared humanity: ‘We are working with a human condition’

• “Life is a terminal condition” (Paula) 6
• “Life is a chronic condition” (Sandra) 9
• “Everybody lives with the unknown” (Dawn) 130
• “We are all going to die one day” (Sandra) 117
• “I think the existential stuff about ‘what do we do while we are here?’ is crucial for everybody” (Paula) 17-18
• “We all struggle with life in some ways” (Paula) 30-31
• “There are many different experiences of being, you know, alive” (Sandra) 1718

• “We’ve all got a chronic condition, it’s the nature of life, you know. We’re all going to suffer. We’re all going to experience pain” (Sandra) 100-101

• “This is life. This is what it is to be human. We are all going to die one day. We’re all going to have limits at some point. We can’t deny that” (Sandra) 116-118

• “It’s just a part of life really, and I quite like that, really, that it’s not something that I’m never going to get” (Susan) 329-330

Focus on shared embodiment: ‘We are all embodied’

• “The groundedness of human experience in the physical body” (Sandra) 188

• “Something that is troubling them that is to do with their physical being” (Paula) 15-16

• “compassionate to your own fragile, human body” (Paula) 174-175

• “I think we are all embodied” (Paula) 17

• “Our experience of the body and our way of being in the body and our way of engaging with the world through our body” (Paula) 179-181

• “Grounded in the fragility of the body” (Paula) 185-186

• “Your body malfunctions and suddenly it’s really hard” (Susan) 288-289

• “It doesn’t get more real than bits of body that don’t work” (Paula) 176-177

• “Engage with what it is to be an embodied being” (Paula) 160-161

• “Understanding what is going on in your body” (Susan) 55-56

• “It’s not just a kind of psychological mental-health issue. It’s about being able to link up body and mind and [...] hold the two parts of your self together” (Susan) 265-269

• “Requires a lot of attention to detail in their own bodies. They need to focus in and notice exactly what is happening in their own bodies” (Clare) 200-202
• “I think that dualism is implicit in a lot of psychology, some strands more than others, and actually when working with chronic illness, you do get past that a bit” (Paula) 197-199

Focus on the individual rather than the illness: ‘I just work with people’

• “There is as many ways it can be as there are people who can have it” (Dawn) 82-83
• “I just work with people” (Sandra) 86, 88
• “Actually people are just people […] whatever label they’ve got themselves or condition they have – there’s a knack to actually seeing the person and not the condition” (Sandra) 106-108
• “You can have a condition and live your life or experience it in two hundred different ways, in two million ways actually” (Sandra) 57-59
• “What gets lost is they end up just presenting the condition and get somehow defined by that” (Sandra) 109-110
• “Identity that’s not grounded on having the illness” (Paula) 148-149
• “Their own personality” (Clare) 110
• “The sort of person they would want to be” (Clare) 246-247
• “I quite like the challenge of understanding what people are like before, what they’re like now and what they want to be in the future” (Susan) 289-292

Redrawing boundaries

Drawing the line between insiders and outsiders: ‘Mentally they are stronger’.

• “Mentally they are stronger” (Dawn) 154
• “Massive range in coping abilities” (Susan) 169
• “People who wouldn’t traditionally see a psychologist” (Susan) 172-173
• “Often a fairly resilient, robust person who has a life already” (Paula) 212
• “Very resourceful, you know, competent, emotionally stable, and have been very sort of ok in their life up till now” (Susan) 144-146
• “I don’t think they’re as willing to be told that they don’t know what they want
(Laughs) - those mental health patients, you know, that what they want is ‘a
symptom of their illness’ (laughs)” (Dawn) 397-399

• “I’ve always sort of not liked that assumption that just because you have a
health condition you can’t cope” (Susan) 148-150

• “People with long-term conditions, they get it. They know when they need a
bit more help and when it’s going be important to make something
happen” (Dawn) 183-184

• “Death and illness don’t frighten me nearly as much as going mad, so there is a
sense in which this is much easier than working with bipolar disorder or
schizophrenia or psychosis [...] that true kind of losing touch with reality,
being plagued in your very soul by voices that torment you or moods that
simply do not respond to any behaviour or things that you do. I find the pain of
working with people who are struggling with that sense of, you know, total
vulnerability and out-of-controlness much harder than working with people in
the, you know, very difficult stages of their illness or towards the end of
life” (Dawn) 140-150

Redefining therapeutic possibilities: ‘You can do a great deal very swiftly’.

• “I like having opportunity to work swiftly” (Paula) 223

• “It’s about working swiftly, more so than in Mental Health [...] That’s the
really important part of it actually” (Paula) 224

• “Within a session you’re off” (Dawn) 169-170

• “There’s a lot you can do, very swiftly, with relatively little work” (Paula)
213-214

• “So I think you can do a great deal very swiftly, whereas in mental health, I
felt that clinical psychologists were often just given the most difficult patients,
who weren’t the ones you could do the most with. And I found that very
frustrating” (Paula) 216-219

• “Behaviourally there is quite a lot of potential, so it’s easier to be there with
the sense of possibilities for change” (Paula) 247-248

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• "The work that we do, because mentally they are stronger, quite small interventions go a really long way" (Dawn) 153-155
• "Often it's a very sort of straightforward process" (Susan) 175
• "It's really exciting to see how a small piece of work with someone they pick up and run with" (Dawn) 155-156
• "They do things we would never have predicted or exactly been aiming for" (Dawn) 156-157
• "The way that people with long-term conditions pick up and run with stuff is really inspiring (laughs) so I love that" (Dawn) 158-160
• "Easier to work alongside and in collaboration with people with long-term conditions" (Dawn) 164-165
• "Most of the work in mental practise is about trying to build a relationship. You can work for years to build a relationship to get to a place where you can start to work with someone and people with long-term conditions, you know, within a session sometimes, certainly within a couple of sessions you’re off and at a very good place in which the trust that enables you to start doing something really quite exciting, so I never was much into deferred gratification (laughs)” (Dawn) 165-172
• "Sometimes we can do a lot to help and sometimes we can’t” (Paula) 245-246
• "Sometimes it can actually be very frustrating working with people who appear to be at pains to try and explain […] how they can’t possibly do anything and to be very closed […] to actually trying” (Clare) 103-106

Different challenges and demands: 'it gives that extra level of complexity'.
• "A lot of the people who I see […] do often have mental health problems too” (Susan) 181-182
• "People who may have 2 or 3 conditions that kind of act together […] so that can be really difficult” (Dawn) 264-265
• "The interaction of a physical illness with a psychological disorder, I think, makes it particularly interesting” (Clare) 149-151
• “I think it gives that extra level of complexity and you have to take into account the different aspects of the physical condition as well as the psychological” (Clare) 183-186

• “There can be a lot more complications trying to work with the two aspects together” (Clare) 170-171

• “This combination feels quite challenging at times, you know, having to deal with such a lot” (Susan) 183-185

• “If you’ve got someone who’s always been very anxious or very avoidant prior to having whatever condition it might be, then you might get into interaction there where it feeds in even more to that” (Clare) 124-127

• “Tease out what the original psychological problems are [...] as well as looking into the impact of the chronic conditions on top of those original anxiety problems” (Clare) 131-134

• “You do have to tailor it rather differently to meet the needs of...given the physical complaints that people might have” (Clare) 173-175

• “I find it really challenging at times and yet incredibly rewarding at times” (Susan) 95-96

Requires good insight and self-awareness: ‘We need to be mindful’

• “Working with chronic conditions is challenging to many therapists” (Dawn) 336-337

• “Notice within oneself that actually there are certain illnesses that really get to you...” (Dawn) 348-349

• “We need to be mindful of what our expectations are and what we expect of ourselves, how we behave in relation to disability or difference” (Sandra) 5961

• “It’s very important to be aware of yourself” (Clare) 99

Beware of ’Idiot compassion’

• “I can’t be hard on you. I have to mother you because that’s how I would like to be treated” (Dawn) 391-392. “I want to be looked after, so I better look after you” (Dawn) 393-394
Increases: ‘Good compassion, good respect, good collaborative working’

- "It feeds the sort of compassion and respect for the people we work with and decreases that “them and us” sense of, you know, it could never happen to me" (Dawn) 371-373
- "At its best, that will mean, you know, good compassion, good respect, good collaborative working" (Dawn) 389-390
- "You do get that good collaborative working" (Dawn) 395-396
APPENDIX H – COUNSELLING PSYCHOLOGY REVIEW NOTES FOR CONTRIBUTORS

1. Length:

Papers should normally be no more than 5000 words (including abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

2. Manuscript requirements:

- The front page (which will be removed prior to anonymous review) should give the author(s)’s name, current professional/training affiliation and contact details. One author should be identified as the author responsible for correspondence. A statement should be included to state that the paper has not been published elsewhere and is not under consideration elsewhere. Contact details will be published if the paper is accepted.
- Apart from the front page, the document should be free of information identifying the author(s).
- Authors should follow the Society’s guidelines for the use of non-sexist language and all references must be presented in the Society’s style, which is similar to APA style (the Style Guide, available from the Society, or downloadable from /publications/submission-guidelines/).
- For articles containing original research, a structured abstract of up to 250 words should be included with the headings: Background/Aims/Objectives, Methodology/Methods, Results/Findings, Discussion/Conclusions. Review articles should use these headings: Purpose, Methods, Results/Findings, Discussion/Conclusions.
- Approximately five key words should be provided for each paper.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.
- Graphs, diagrams, etc., must have titles.
- Submissions should be sent as e-mail attachments. Word document attachments should be saved under an abbreviated title of your submission. Include no author names in the title. Please add ‘CPR Submission’ in the e-mail subject bar. Please expect an e-mail acknowledgment of your submission.
- Proofs of accepted papers will be sent to authors as e-mail attachments for minor corrections only. These will need to be returned promptly.

3. Publication ethics: All submissions should follow the ethical submission guidelines outlined the documents below:
4. Copyright

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Counselling psychologists and teachers of psychology may use material contained in this publication in any way that may help their teaching of counselling psychology. Permission should be obtained from the Society for any other use.

5. Abstracting and indexing coverage: PsycINFO

6. The Review Process:

Counselling Psychology Review is a peer reviewed research publication. Each paper submitted will be subject to two phases of review. Initially the Editor will clarify the general quality and relevance of the paper prior to it being reviewed by at least two individuals who have some familiarity with the subject matter (either the subject matter or methodology adopted). Once these reviews have been completed, the Editor will provide a brief report summarising the findings and outlining the final decision on the paper. This process should take no more than three months.

If the paper has been accepted then the timescales for publication will be provided where possible. In the instance that revisions are requested, individuals are asked to undertake these within a three month period. The Editor will review the updated work in the first instance and may resend it to one of the original reviewers for further comments. A decision will be made as soon as possible however for the purposes of clarity this will be within three months of the resubmission.

An overview of the guidance provided to reviewers will be made available on request.

6. Submissions and enquiries should be emailed to:

Dr Terry Hanley - terry.hanley@manchester.ac.uk