

**Help-seeking in the event of psychological distress:
A qualitative exploration**

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Abstract

Aim

This thesis explores the seeking of help from a General Practitioner in the event of psychological distress. The study explores help-seeking, lay understanding around mental health, and the relationship between the two.

Background

Help-seeking has been shown to vary according to different demographic factors, and is not necessarily correlated with need. Frequently, those who need help most do not seek it, whilst those with low need are more likely to enter care; help-seeking is complex, and there is value in understanding more about current patterns. Lay knowledge is perceived as playing a crucial role in help-seeking, providing rationale for examining the two alongside each other.

Method

Qualitative interviews were used to explore the stories of people who have recently sought help, alongside interviews from a group of 'lay' participants who discuss distress, help-seeking and mental health more generally. 20 interviews were carried out, analysed using a combination of thematic analysis and the process of analytic induction.

Findings

The thesis sheds light on the *limited* role of lay knowledge; its role is most evident when considering *hypothetical* help-seeking. For recent help-seekers, journeys towards care were mediated by factors pertaining to their wider lives; help-seeking was intimately related to their context. Help-seeking is the outcome of a complex interplay of factors and the study sheds light on aspects of individuals' stories that render distress *more or less* likely to enter Primary Care. The process of medicalisation is illuminated, for example, individuals receiving care for *physical* health problems are particularly prone to their distress being medicalised. Findings lend support to a contextually-rooted approach to understanding help-seeking. Expectations of – and preferences for – care are explored, evidencing a need for General Practitioners to consider

referral to self-help and/or support groups within the community; individuals may not necessarily be seeking a medicalised response.

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Abbreviations and citing conventions

Abbreviations

AI	Analytic Induction
CASE	Collaborative Awards in Science and Engineering
CBT	Cognitive Behaviour Therapy
CEP	Centre for Economic Performance
COA	Cycle of Avoidance
DH	Department of Health
DNA	Did Not Attend
EOI	Expression of Interest (form)
ESRC	Economic and Social Research Council
GP	General Practitioner
HBM	Health Beliefs Model
IAPT	Improving Access to Psychological Therapies
ID	Index of Deprivation
IMD	Index of Multiple Deprivation
NEM	Network Episode Model
NHS	National Health Service
NRES	National Research Ethics Service
PIS	Participant Information Sheet
PCRN	Primary Care Research Network
PCT	Primary Care Trust
REC	Research Ethics Committee
SBM	Socio-Behavioural Model
SES	Socio-economic Status
SOA	Super Output Area
SRA	Social Research Association
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
UK	United Kingdom

Citing conventions

When citing a published source, words are spelled according to their original source, for example, the American spelling of the word ‘behavior’ is cited even if this differs to its usage in the remaining body of the thesis.

When citing published work, an ellipsis ‘...’ is used to denote removed text.

However, when citing the speech of study participants, the same use of ellipses ‘...’ denotes a pause in their speech. This is in order to include pauses within participants’ quotations, so that speech can be read in a manner that represents its utterance. When indicating that participants’ speech has been omitted, ellipses within squared brackets ‘[...]’ are used instead.

Chapter 1

Introduction

This thesis is about the seeking of help in primary care when experiencing psychological distress. It is a sociological investigation – indeed from the perspective of medical sociology – into how and why people within Nottingham seek care from their General Practitioner (GP) when experiencing such distress. This introductory chapter will briefly provide some context to the study, explaining why help-seeking is a matter of contemporary interest. Greater context for study will be given in chapter 2 (the literature review), however an introduction is given here, along with the research questions, so that the purpose and aims of the study are explicit from the outset. I will then outline the contribution of this study – which is to illuminate the process of help-seeking and its inseparability from a person’s wider context – so that the study’s main theoretical contribution is understood. I will then provide an outline of this thesis’ chapters, summarising how each chapter contributes to the overall findings of the study. As well as shedding light on the importance of context, the study provides insight into specific nuances of seeking help, and when and why an individual’s distress might come to be ‘medicalised’.

Context of the study

As mentioned above, this thesis explores how and why people within Nottingham seek care from their GP when experiencing psychological distress. Much is known about the different rates of consultation that can be found within the United Kingdom (UK) population, for example, that women seek help for distress more than men. But the figures mask complex processes that lead to such statistics, such as different levels of distress between groups, differing access to resources, and differing ways of responding to distress, to name but a few. The underlying problem relating to help-seeking is that frequently, people with high need of help do not seek it, whilst people with low need do. This is an oversimplification that will be explored more in the literature review, however this is the underlying problem pertaining to help-seeking: why do some people seek help, and not others?

The study began as a CASE studentship (Collaborative Awards in Science and Engineering) that comprised a funding partnership between the Economic and Social Research Council (ESRC) and NHS Nottingham City, the Primary Care Trust (PCT) that delivers healthcare for the city of Nottingham. The study was created to investigate help-seeking within Nottingham, and to see whether specific beliefs around mental health treatment might be shaping demand for services. The impetus for the study was derived out of experience within the PCT (Ian Shaw 2008, pers. comm.) that despite high initial demand for care, referral to psychological therapies yielded a low rate of attendance (that is, a high rate of DNAs, 'Did Not Attend'). The study was therefore designed to explore lay understanding around mental health and to consider its impact upon the help-seeking process: do people hold beliefs around treatment that lead to high demand, but that might then culminate in failure to attend a referral?

Current levels of help-seeking within primary care are high; recent figures from the Department of Health (2008) indicate that one third of GPs' time is spent on mental health issues and that one in six UK adults has a common mental health disorder. According to NICE (National Institute for Clinical Excellence), common mental health disorders account 'for one in five of all work days lost and cost UK employers £25bn each year' (NICE 2011b). NICE suggest that:

at any one time common mental health disorders can be found in around one in six people in the community, and around half of these have significant symptoms that would warrant intervention from healthcare professionals. (NICE 2011a, p.19)

Thus, the prevalence of common mental health disorders is perceived as high. Different theoretical perspectives are discussed within the literature review that provide alternative explanations and suggest that such statistics are not necessarily an accurate indication of the prevalence of mental illness. One such explanation is De Swaan's (1990) argument that individuals have come to reshape their 'troubles' as 'mental health problems', and that distress is increasingly viewed through a medical lens – distress is being *medicalised*.

With such arguments in mind, a study pertaining to lay understanding was viewed as highly relevant; indeed, greater understanding of what might increase the likelihood of help-seeking, and what might inhibit it, has salience to current healthcare delivery. As will be discussed, lay understanding is viewed as crucial to the process of help-seeking.

This thesis takes a novel approach to the study of help-seeking. It explores help-seeking alongside lay understanding, as two separate phenomena and also as phenomena that are potentially related. There is a perceived relationship between the two that is discussed in the literature review, although both areas are initially explored individually to allow the potential for insight to arise that is *not* derived from their relationship. Thus, the possibility of insight into their relationship, as well as other factors that may be salient, is created. By studying lay understanding and help-seeking, the thesis explores what factors might influence help-seeking, and creates the opportunity to explore whether expectations around care that are reminiscent of De Swaan's reframing of troubles might underpin increased demand for care.

As will be outlined in the literature review, I address previous research related to help-seeking and focus upon what I term 'the help-seeking problem'. Whilst it may be premature to highlight the problem here (indeed, this definition is most suited to the literature review where supporting arguments precede it), I will do so briefly here so that the research questions below are viewed in context. I define 'the help-seeking problem' thus:

There are very high rates of help-seeking and the causes of this trend are unclear. Apparent trends within help-seeking figures – that certain groups consult more frequently than others – cannot readily be explained with reference to need. There are groups that access care less readily than others, potentially culminating in more serious manifestations of distress if left untreated; there is also a high prevalence of 'low need' individuals who seek care. It is not yet fully understood why these observed differences are as they are, and there is potential importance in helping those who most need care in accessing it, whilst at the same time understanding why there are high levels of help-seeking elsewhere.

It is within this context that this study locates itself. Specifically, it seeks to examine lay understanding alongside help-seeking, to explore its potential influence. This significantly shapes the study design.

The research questions are discussed in more depth in chapter 3, however I will introduce them here so that the inquiry that drives this thesis is clear from the outset. The overarching research questions are:

According to the accounts of individuals, when and why do some people seek help from their GP when experiencing distress? And what role does lay understanding play in this?

The study also addresses three sub-questions that address the topics of lay understanding and help-seeking in isolation, and then together, so that when viewed as a whole they provide insight into the overall research question. The sub-questions are:

1. How do 'lay' participants conceptualise 'mental health', 'mental illness', and distress? And what expectations are there around care?
2. What reasons do recent help-seekers give for seeking help when they did? What expectations did they have of care, and what other factors played a role?
3. What is the nature of the relationship between lay understanding and help-seeking?

Based upon recent interpretivist work relating to help-seeking (Biddle *et al.* 2007), and a trend within literature that emphasises the importance of the *meanings attached* to illness and seeking help, the study design employed methods that elicited in-depth views from participants. This was intended to garner insight into the views and experiences that culminated in seeking help, based upon the individual's attribution of meaning to their experience. The thematic findings, however, point towards the salience of individuals' wider lives to their process of help-seeking, and for some the experience and interpretation of distress is inextricable from their wider social lives, as opposed to focusing upon the meanings attached to illness or seeking help. The study therefore shows insight into the contextual nature of individuals'

trajectories. In responding to the different research questions, different aspects of individual's contexts are illuminated, throughout the thesis. As well as providing insight into the relationship between help-seeking and lay understanding, the study illuminates other contextual factors pertaining to help-seeking (*i.e.* broader aspects of a person's life such as access to alternative forms of help and support (*e.g.* workplace counselling) or concurrent physical health problems) that provide insight into why some individuals seek help when they do (and why some individuals do not). These factors exceed the role of lay understanding, and show how a person's wider life enables or hinders help-seeking just as it might affect a person's levels of distress. This reflects the salience of older studies – in particular the work of Zola (1973) – who demonstrates that help-seeking reflects other aspects of an individual's life *in conjunction* with their 'illness'. Thus, the study provides support for an approach that views help-seeking as the outcome of a complex interplay of factors that cannot be reduced to the simple 'determinants' or demographic factors that are frequently the receipt of focus (for example, 'need', 'severity', gender and age, as will be discussed in the literature review). Recent work of Pescosolido (2011) locates a person's context as related to the cause of their distress as well as the consequences, and this study provides support for such an emphasis upon context. The study also illuminates some of the more subtle factors that shape why some individuals are particularly likely to come into care, and why some are not.

The theoretical contribution of this study is that it provides insight into theorising help-seeking, and also into the role of lay understanding in the process of help-seeking. It helps to illuminate the *limitations* of lay understanding in determining help-seeking, and that help-seeking *is not necessarily an individualised process*; thus, a focus upon lay understanding (as a determining factor), or any model that assumes purposive action on the part of an individual, may be insufficient. This thesis also sheds light on aspects of an individual's life that might hinder or enable help-seeking, and why distress may come to be viewed as amenable to medical help. The study provides insight into what individuals might perceive as beneficial in the event of distress; this has potential policy relevance, and the study highlights a potential

disparity between what individuals view GPs as being able to provide, and what GPs themselves might be likely to provide.

Structure of the thesis

I will provide a brief chapter outline so that the structure of this thesis is explicit:

Chapter 2 provides a review of the relevant literature. It begins with a brief history pertaining to the origins of the concept of ‘mental illness’ and its associated treatment, so that the study’s approach, which is to view mental illness as a temporally-specific concept whose current definition and treatment is shaped by a range of factors, is underlined. It then provides an overview of the concept of help-seeking – an aspect of ‘illness behaviour’ – and the conflicting patterns that exist within primary care that defy simple explanation. The chapter then proceeds with an overview of lay understanding, the implications of and reasons for studying the term, and what is known about lay understanding in an international and UK context. The background to the study of the two concepts – help-seeking and lay understanding – is then explained with reference to literature that suggests the two are interlinked. The concept of medicalisation is then introduced, as this pertains to the process of viewing emotions and/or behaviour through a medical lens, a process that underlies help-seeking to some extent (this will be more fully explained and challenged throughout the thesis). The chapter then finishes with an explanation of the study’s ontological and epistemological position, in order to provide clarity as to the use of the term ‘mental illness’ from the perspective of weak constructionism (Hacking 2003). When conducting a study related to mental health from a sociological perspective, it is essential to clarify one’s ontological position regarding the reality of the concept of ‘mental illness’ itself.

Chapter 3 provides an overview of the study design and implementation, along with the research questions. It locates the study as a qualitative interpretivist investigation that explores lay understanding and help-seeking through the stories of people in Nottingham. The study involves interviews with people who have (‘help-seekers’) and have not (‘lay participants’) sought help for psychological distress. The reasons for such an approach, which are

explained more fully in chapters 2 and 3, is that in order to elicit lay understanding that has not been shaped by healthcare professionals, it is necessary to speak to people who have not had their views shaped by the receipt of mental health care. In addition, in order to understand the process of help-seeking, it is necessary to speak to people who have sought help. Thus, the study comprises interviews with these two different groups.

Chapter 4 provides data and analysis relating to the lay participants. It provides insight into both the *nature* and *content* of lay understanding; it is important to understand both as the utility of lay understanding (as a concept) is tempered by its idiosyncratic and changeable nature. Nuances of views amongst the public are explored that shed light on when individuals might choose to view someone's (or their own) experience as a 'mental health problem', and when appropriate care might be sought. Views on appropriate care are also discussed. The chapter sheds light on the perceived consistency between lay understanding and hypothetical help-seeking, as well as the context in which help-seeking decisions are made. It provides a depth of insight into lay understanding that is original within a UK context.

Chapter 5 explores the experiences of help-seekers, and focuses upon the process of interpretation that was, or was not, experienced. The chapter explores specific individuals' experiences to highlight difficulties in actually ascertaining that something was 'wrong'. The chapter goes on to illuminate the importance of help-seekers' contexts as both a factor in their distress, and also a factor in the recognition of 'a problem'. It highlights the experiences of individuals whose presence within medical care (for physical health problems) rendered their distress as particularly amenable to medicalisation, and this is an original insight. The salience of individuals' contexts to their help-seeking trajectories is emphasised; stories are grounded in, and inseparable from, their context. Lay understanding is viewed as playing only a limited role in their stories, alongside other more immediate factors including the consequences of distress itself, the occurrence of unexpected events and the failure of other resources to alleviate distress. The data contributes to a shift that is currently taking place within help-seeking research towards viewing help-seeking as contextually-located, by providing supporting data that was derived from an interpretivist UK-based study.

Chapter 6 explores participants' expectations of care (if any were present) and examines the views of both groups to consider how they align with the services that a GP is able to provide. This chapter therefore provides the opportunity for recommendations regarding service provision, and shows the potential for useful signposting that is not apparently given within consultations (based upon participants' experience) even though such signposting is potentially within the remit of a stepped care approach (NICE 2011a). Such insight forms the basis of an original finding. The chapter also reflects upon whether expectations of care played a role in participants seeking care, and provides insight into the process of medicalisation that takes place when a GP provides a medical *response* to an individual's distress (and not necessarily before). The chapter shows how contemporary beliefs around mental health, and appropriate care, interact with the UK healthcare context.

Chapter 7 provides a reflection upon the study and shows how it contributes to elucidating the context of help-seeking within the UK. It reiterates the main findings regarding how the study has answered the research questions, namely, by shedding light on the limitations of the relationship between lay understanding and help-seeking, because of its inherently *contextual* nature ('contextual' referring to a person's broader life, including their access to other resources). This chimes with the current focus of Pescosolido's (2011) work, yet is derived from an approach that differs to that of Pescosolido's, reinforcing the salience of similar findings. In addition, the study has shed light on specific nuances of why people experiencing significant physical health problems might be particularly likely to come into care for distress. It shows the process of *partial* medicalisation of distress on the part of individuals, and why there might be a mismatch between what individuals *expect* a GP to be able to provide, and the response they might *actually* receive. The chapter then reflects upon the study limitations and upon the researcher's own role in the study. By shedding light upon the context in which help-seeking decisions are made, and the difficulties of interpretation that help-seekers face when experiencing distress, the study deepens understanding of when and why distress might come to be viewed, or not viewed, as something that may benefit from help from a GP.

Chapter 2.

Defining the context of ‘the help-seeking problem’

This chapter provides a review of the main bodies of literature relating to the study. As the study draws upon an assumption that an individual’s behaviour in the event of distress may reflect current approaches to distress, it is necessary to provide some support to the notion that distress is a contextually-specific phenomena. This is done by providing a very brief history to the concept of ‘mental illness’ and how it is construed in the present day, including the range of professions that attend to distressed individuals and the broad remit of what is encompassed by the term ‘mental health problems’. Whilst it is a ‘well-rehearsed argument’ (Rogers and Pilgrim 2005, Busfield 2011) that the current concept of ‘mental illness’ has its roots in history, it is nonetheless worth repeating some of the key messages that come out of such an assumption. The chapter then moves on with a review of the literature pertaining to help-seeking, and explores some of the difficulties that are apparent in understanding rates of help-seeking in a contemporary context; this section defines ‘the help-seeking problem’. I will also explore some of the recent developments within help-seeking research, as this study reflects such recent developments in its design. I then explore literature around lay understanding, discussing the concept (and its limitations) before exploring what is already known about lay understanding, and how it might usefully be applied to help-seeking. I then discuss the concept of medicalisation, as well as related arguments that discuss potential alternative explanations for the increased prevalence of mental illness that can be found in recent surveys. This helps to provide a range of different potential explanations that might underlie recent increases. Lastly, the chapter explores this thesis’ ontological and epistemological position; in order to carry out a sociological study related to mental health, it is necessary to consider the reality of the concept, and this is most usefully achieved whilst simultaneously addressing the study’s epistemic underpinning.

A brief history: the evolution of ‘mental illness’, and mental health care, within the UK

In order to locate this thesis within the field of the sociology of mental health and illness, it is necessary to provide some background to the topic of ‘mental health’ as a concept within the UK. By illuminating some of the history of the term, its contextual specificity is highlighted and its current form within broader society can be viewed as evolving and interactive. This history focuses solely on the UK for reasons of brevity; it is acknowledged that the historical development of the concept of mental health, and its corresponding treatment, is a complex product of factors including international. However, because the study is aimed at help-seeking and lay understanding – both viewed as culturally influenced to some extent, as will be described in more detail in the corresponding sections below – *within the UK*, its historical context requires illuminating most clearly. I will provide a very brief history of the concept, that necessarily skips across large swathes of policy and social developments; this is so that its purpose, which is to illustrate four main points, can be done in a concise manner. These four main points are: to show the evolving nature of the concept and some insight into why it evolved as it did (*i.e.* some of the social movements that fed into its development); to identify the main different treatment approaches and some insight into their history; to highlight the broad range of different professional roles in the field; and to show the evolution of the variety of different problems that fall within its remit. This will then situate the current study, which examines contemporary views around mental health alongside the process of seeking help, in a broader historical context. Much fuller reviews of the history of the concept (and the associated ‘treatment’ responses) within the UK are provided elsewhere. This history will start with the developments that arose following the First World War.

Developments that followed the First World War: a shift in perceptions and treatment methods

Prior to the First World War, mental illness was largely treated in asylums, and with a focus upon biological treatment. For a number of reasons, asylums were very crowded and conditions were poor; treatment was therefore

reserved for those whose problems were severe (Jones 1972, Jones 1993). The experience of 'shellshock' following the First World War created a shift in how people viewed mental ill health. Following the return of soldiers experiencing shellshock, previous views (fuelled by the Eugenics movement, about the role of 'faulty genes') were challenged, and it was then seen as something that could affect anyone and was not necessarily hereditary (Jones 1972, Jones 1993, Rogers and Pilgrim 2005, Horwitz and Wakefield 2007). Following the treatment of shellshock using both psychiatric and psychoanalytic methods, the professions of psychiatry and psychology both increased in status (Rogers and Pilgrim 1996). However, it was the psychiatric profession that was viewed as the dominant profession, and this remains the case to the present day (Busfield 2011). After the First World War, treatment methods were more 'eclectic' (Rogers and Pilgrim 2005, p.142), with 'neuroses being treated psychologically and madness being treated with physical means' (Rogers and Pilgrim 2005, p.142). The 1930 Mental Treatment Act introduced the possibility of voluntary in-patient treatment as well as a different non-voluntary certification, for 'temporary' use (Fawcett and Karban 2005); the term 'mental hospital' also came into use, replacing the term 'asylum' (Fawcett and Karban 2005). Despite the increase in use of hospital-based somatic psychiatry during the inter-war period, the Second World War sparked an increase in the use of psychoanalytic methods of treatment (Rogers and Pilgrim 2001) specifically in the army psychiatric services. Arising from an awareness of the problems of shellshock, new innovations were implemented for the army patients, such as the introduction of small group psychotherapy and therapeutic community approaches (Rogers and Pilgrim (2001), drawing from the work of Jones (1952), Main (1957) and Bion (1961)); however, despite the use of psychological methods during the war, and the increase in confidence in those methods, the post-war era saw a return to biological psychiatry (Rogers and Pilgrim 2001).

The beginning of deinstitutionalisation and treatment within the community

In the 1950s, there was concern over the severe crowding of mental hospitals and a huge economic burden associated with maintaining the buildings (Jones 1972, Jones 1993). Jones (1972, 1993) argues that alongside

this economic burden, three ‘revolutions’ emerged that contributed to deinstitutionalisation, however Jones’ conservative analysis is contested. I will briefly summarise it here so that the changes it focuses upon are highlighted. Jones suggests that a ‘social revolution’ occurred, with the start of the ‘open-door’ (Jones 1972, p.291) movement in hospitals, moving treatment more into the community so that hospital treatment represented only a part of care. A ‘legal revolution’ began with the appointment of a Royal Commission, which sparked a movement for the reform of the law (Jones 1972) leading to the mental Health Act of 1959, which cemented the government’s intention to move care away from institutionalisation towards care in the community (Jones 1972, Jones 1993). Jones (1993) suggests that a ‘pharmacological revolution’ took place in the early 1950s with the development of new drugs for the treatment of mental illness, and that new drugs offering relief from some of the symptoms of mental illness enabled a reduction to take place in the number of patients in mental hospitals. However, Rogers and Pilgrim (2005) point out a number of flaws in this latter argument in particular, most notably that deinstitutionalisation began before such medication was introduced, and they caution against reliance upon Jones’ interpretation.

Other factors argued as playing a role include the anti-psychiatry movement, which gained momentum following the publication of important theoretical critiques of the prevailing approaches to the treatment of mental ill health. Goffman’s (1961) ‘Asylums’, Foucault’s (2007 [1961]) ‘Madness and Civilisation’ and Thomas Szasz’s (1970) ‘The Manufacture of Madness’ called into question the power of the psychiatric profession, the validity of their treatments and the validity of the concept of ‘mental illness’ itself. The ‘Rosenhan Experiment’ (Rosenhan 1973) also lent weight to these critiques, providing a chilling example of the fallibility of psychiatrists in delivering a legitimate diagnosis and recognising ‘sanity’. These events occurred at a similar time period as a political desire to reduce the economic burden of care (Carpenter 2000), and a move towards care in – and by – the community took place (Fawcett and Karban 2005). However Rogers & Pilgrim (2005) caution against reliance upon any one explanation for deinstitutionalisation, including that of the anti-psychiatry movement, and provide a useful and detailed discussion of differing perspectives that may have contributed each in small

part. For the purpose of this review, this range of factors will suffice; it is important to concede that such developments are a product of micro, meso and macro factors¹ (Pilgrim and Rogers 1999, Carpenter 2000). Rogers and Pilgrim (2005) point out that treatment within the community has had success for some individuals; however, they also point out that treatment within the community includes treatment within inpatient psychiatric wards that show less positive outcomes for similar reasons to treatment that occurred within asylums (namely, a focus upon biomedical treatment, the use of compulsory detention and a poor social environment (Rogers and Pilgrim 2005)). Following deinstitutionalisation and the shift away from the use of asylums towards care within different parts of the community (including for those with less severe difficulties), the number of different professions involved in the care of people with mental health difficulties has increased (Busfield 2011).

The growth of different professions, and the contemporary policy context

Busfield (2011) suggests that the growth of different professions involved in mental health care provides some counter to the previous hegemony of psychiatry in this area:

Some have argued that since the 1950s psychiatrists' dominance over the field of mental health and illness has, in some respects, been weakened, not least by the emergence of new groups of 'psy' professionals – that is, practitioners and academics focusing on the mind or psyche, such as psychoanalysts, psychotherapists, clinical and health psychologists, mental health nurses and psychiatric social workers, with whom psychiatrists are, to some extent, in competition. (Busfield 2011, p.2)

although she argues that the psychiatric profession remains dominant in this field of care. A variety of different types of service now fall within the remit of community care, as Rogers and Pilgrim (2005) describe:

¹ Pilgrim & Rogers (1999) define these factors as micro: 'the actions and interactions of interest groups and their constituent individuals' (p.15); meso: 'national and cultural policy legacies and trends' (p.15); and macro: 'global, transcultural or transhistorical factors' (p.15)

Community care is constituted by a variety of activities and services. The main initiatives evident over the past 20 years include psychiatric services in primary healthcare settings, the expanded use of community psychiatric nurses, the development of community mental health centres, the provision of domiciliary services, the development of residential and day care facilities, an increased emphasis of voluntary services and informal care by relatives and friends, and the relocation of mental health responsibilities from the secondary care sector to primary care. (Rogers and Pilgrim 2005, p.182)

Since treatment shifted closer to the community, different sites of treatment have proliferated and this has also led to a greater number of associated roles. Rogers and Pilgrim go on to point out that ‘Mental health provision in Britain is still largely hospital-based’ (p.182), however it is possible to see the extent to which care has been brought closer to ‘home’, and within the remit of primary care. At this point it is salient to provide a brief insight into the contemporary policy context so that the current climate of treatment and service provision, and the rationale underpinning them, is more clearly outlined.

Since deinstitutionalisation, the shift towards care within the community has had its own controversies, most notably in relation to fears around dangerousness; in the 1990s, a number of attacks that took place in Britain fuelled concern over dangerousness (Fawcett and Karban 2005), leading to a shift in policy towards a disproportionate focus upon risk (Pilgrim and Rogers 1999). Care within the community has since battled to balance the competing concerns of care and control. Lester and Glasby (2006) suggest that this is the ‘central paradox at the heart of mental health policy and practice’ (p.48). The issue of control (indeed, the wider issue of social control (and deviance) that is a concern for sociologists in the area of mental health) is not central to the point of this historical summary and so will necessarily be sidestepped, suffice to say that it is acknowledged as a broad area of literature that permeates discussion of mental health care (and associated policy), from the work of the anti-psychiatrists mentioned above, and Zola (1972) onwards. For the purposes of this review, the requirement for the issue of ‘control’ to feature within mental health policy and practice is acknowledged.

The provision of mental health care, in relation to the wider area of healthcare provision, has been termed as having ‘Cinderella’ status by many (for example, Rogers and Pilgrim (2005) and Lester and Glasby (2006)). Under the previous (Labour) government, reform of services was taking place to improve mental health services and bring them closer to those of physical health; increased investment took place, albeit not evenly across sectors (Lester and Glasby 2006). The remit of the NHS was stated as broadening from one focused upon *sickness* to one focused upon *health* (DH 2004) and a broadening of this remit in relation to mental health can also be seen, for example, in the concept of mental health promotion: ‘Mental health promotion involves any action to enhance the mental well-being of individuals, families, organisations or communities’ (DH 2001, p.27). In the Department of Health publication *Making it Happen: A guide to delivering mental health promotion* (2001), the topic of mental health is described as relevant to *all*, not just those who are *ill*, and the salience of good mental health (and of mental health promotion) to other aspects of a person’s life is expounded:

Everyone has mental health needs, whether or not they have a diagnosis of mental illness. These needs are met, or not met, at home, at work, on the streets, in prisons and hospitals, in schools and neighbourhoods – where people feel respected, included and safe, or on the margins, in fear and excluded. Because everyone has mental health needs, the need for mental health promotion is universal and of relevance to everyone. Mental health promotion does have a role in preventing mental health problems, notably anxiety, depression, drug and alcohol dependence and suicide. But mental health promotion also has a wider range of health and social benefits. These include improved physical health, increased emotional resilience, greater social inclusion and participation and higher productivity. (DH 2001, p.28)

A shift away from only *sickness* towards a greater concern with *health* and *well-being* broadens the remit of healthcare provision; notions of ‘healthiness’ move away from simply being the ‘absence of illness’ and this marks a clear contrast to earlier notions of ‘mental illness’ as a specific focus of policy

concern. Mental health policy now shows greater awareness of the burden associated with ‘common mental disorders’ as an area of focus (see, for example, the *National service framework for mental health* (DH 1999)), with such disorders being amenable to treatment within primary care. The government’s programme of Improving Access To Psychological Therapies (‘IAPT’, announced in 2007) was based upon the treatment success evidenced by certain psychological therapies, in particular CBT (Cognitive Behaviour Therapy) in helping people with depression and anxiety disorders (Clark *et al.* 2009). The costs associated with this could be more than offset by the savings that could be made through helping people suffering from anxiety and depression, by helping them return to work and reducing the costs associated with medical treatment and welfare benefits (and recouping the benefits from extra taxation) (Clark *et al.* 2009). The rolling out of the IAPT programme has been taking place since 2008, and is expected to continue for a further three years (DH 2012), addressing the burden of care associated with the prevalence of anxiety and depression; indeed, evidence of its benefit to employment (and the associated reduction in welfare payments) for those who have used it so far is provided (DH 2012).

Current policy represents a shift towards raising the importance of mental health care to that of physical health (‘parity of esteem’ (CEP 2012, DH 2011)), and this is likely in no small part related to the perceived economic benefits mentioned above. The coalition government has continued to place mental health high on its health agenda (as per the document ‘*No Health Without Mental Health*’ (DH 2011)), although this is now amidst wider structural changes that are taking place within the NHS that are beyond the remit of this summary. One of the main aims of this ‘fifth phase’ of the history, is to evidence a policy context that has a much broader remit in terms of mental health care than ever before, a context that has broadened the limits of its boundaries of care to include a focus on ‘well-being’ and not just sickness. A discussion on specific *measures* of well-being (and its appropriate definition) is pertinent to contemporary research in this area, and is widely discussed elsewhere, for example, the work of Layard (2010). The remit of mental health services has changed significantly in recent times. Rogers & Pilgrim (2005) summarise the developments succinctly:

during the twentieth century the ambit of psychiatry changed in a number of ways. By the end of that century mental health services also dealt with a range of other problems, such as neurosis, personality disorder and substance misuse... At the same time, it was becoming evident that conditions such as depression (the ‘common cold of psychiatry at once familiar and mysterious’ (Seligman 1975)) and ‘anxiety’ could be contained in primary care. The great majority of patients with these ‘common mental disorders’ either did not seek help or were treated only by GPs, an arrangement still applicable today. Thus the remaining picture is that the bulk of people deemed to have mental health problems never access specialist services. (Rogers and Pilgrim 2005, p.179)

As Rogers and Pilgrim point out, the perceived ‘bulk’ of people with mental health problems are now treated outside of specialist services (within primary care) and are associated with ‘common mental disorders’ that can be dealt with in primary care, although they also point out that many individuals with such problems do not seek care. Thus, the remit of mental health care has shifted towards inclusion of ‘common mental disorders’, and consequently a shift in the types of services provided (and the associated ‘burden of care’) has also taken place.

To summarise this brief history, the delivery of mental health care has evolved from treating only severe problems, in asylums, towards a context where mental well-being is widely discussed and is perceived as relevant to everyone; the concept of ‘mental illness’ has shifted towards a greater focus upon ‘mental health’. What is considered treatable (and also, an illness) has also broadened to include Seligman’s ‘common cold of psychiatry’ (Rogers and Pilgrim 2005, p.179, citing Seligman (1975)). Whilst treatment was at one time only available for those within asylums, treatment is now possible within the community, and for a number of much less severe difficulties (as compared to those treated within asylums). The history of the professions pertaining to the treatment of mental ill health has developed over a long period of time, in conjunction with world events that have shifted how treatment and causation are viewed. There is a plurality of views in relation to the causation of mental health problems and in relation to treatment; the summary shows how the use

of treatments from psychiatry and psychology varied over the period from the First World War onwards, culminating in the continued dominance of psychiatry. The number of professions involved in mental health care is now large, following the shifting of care towards non-institutionalised contexts; care is now delivered by a number of different people in a number of different contexts, from psychiatric wards to in the home, with many people not coming into contact with specialist services. A shift has occurred toward primary care as a significant arena for delivery of care, and whilst the psychiatric profession likely retains dominance, there are now a number of other professionals who also address the population's needs. It is within this context, that this study seeks to explore what beliefs members of the public hold around mental health (and mental illness), and what factors (including such beliefs) might influence attendance within primary care.

To provide some context for this study, as mentioned in the introduction, recent figures from the Department of Health (2008) indicate that one third of GPs' time is spent on mental health issues and one in six UK adults has a common mental health disorder. These alarming numbers suggest that not only is there a significant burden upon the NHS, but also upon welfare services and the wider economy through associated disability. According to NICE, common mental health disorders account 'for one in five of all work days lost and cost UK employers £25bn each year' (NICE 2011b). However, there is contention amongst researchers as to what might actually underlie these figures (and in particular, why they have been increasing to their current level (Middleton and Moncrieff 2011)), with various potential causes and solutions being proposed. This literature chapter will address some of the potential alternative explanations so that potential explanations can be considered within the study.

Having justified a theoretical approach that views mental illness – and its associated treatment – as contextually-specific, and illuminated some shifts that have taken place in what is now within the remit of 'treatment', I will now turn to literature that addresses help-seeking specifically. This literature comprises the study of help-seeking, why it is viewed as important, and how it is currently approached.

Introduction to the study of help-seeking: what is help-seeking, and why study it?

The term help-seeking refers to one aspect of 'illness behaviour' and therefore it is useful to consider the broader term 'illness behaviour' before focusing upon help-seeking *per se*. Illness behaviour is a term coined by Mechanic and Volkart (1961) to describe:

the way in which symptoms are perceived, evaluated, and acted upon by a person who recognises some pain, discomfort, or other signs of organic malfunction (Mechanic and Volkart 1961, p.52).

The concept addresses the ways in which individuals respond to changes in their health, perceive and evaluate what is happening, and decide what action to take including tolerance of the problem. Mechanic (1995) suggests the concept of illness behaviour was first alluded to in 1929 by Henry Sigerist and then elaborated by Parsons in his concept of the 'sick role' (Parsons 1951). Since Parsons' work, the concept of illness behaviour has received significant attention and continues to attract theorists attempting to model or otherwise account for variances in the behaviour of individuals upon the onset of symptoms of illness. It is useful here to point towards a well-cited distinction between 'illness' and 'disease'. 'Disease' is a biological event, pertaining to an individual's body and any associated changes arising from organic disruption; '*disease* is something that physicians diagnose and treat' (Radley 1994, p.3, emphasis in original). 'Illness' is the social response to a disease, what Freidson (1970) calls 'a social rather than biological state' (Freidson 1970, p.206) and encompasses various aspects of an individual's response to bodily changes, including modifying their behaviour or otherwise (for example, by taking time away from work); '*Illness* can be taken to mean the experience of disease, including... the consequences of having to bear that ailment' (Radley 1994, p.3, emphasis in original). Mechanic (1995) provides a later, more detailed description of the concept of illness behaviour:

Illness behavior refers to the varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret

symptoms, make attributions, take remedial actions and utilize various sources of informal and formal care. Such behavior is important because it shapes the recognition of illness, the selection of patients into care, the degree of compatibility between patient and physician attributions, patterns of health practice and adherence with medical advice, and the course of illness and the treatment process. (Mechanic 1995, p.1208)

An individual's illness behaviour is thus inherently contextual; not only is it based upon their assessment of the problem (which, as discussed in the section below, takes into account culturally specific ideas about health) but also in their consideration of different potential actions, the range of which is delimited by a person's wider social context. Help-seeking is only one part of the wider term illness behaviour (Mechanic 1978a), and yet it is important to locate help-seeking as part of this broader term so that help-seeking itself is located culturally, and as part of a broader range of processes. Help-seeking is the process of accessing help for a medical (or suspected medical) problem (Freidson 1970); whilst it mostly relates to accessing *formal* care (that is, care provided by an organisation, whether NHS, community-based or other), the process of help-seeking is likely to include accessing informal care, help and advice, such as that of family and friends. In relation to mental health in particular, not all care that is received is accessed voluntarily, and so accessing of care *per se* is not necessarily synonymous with *help-seeking*. However, this study does not focus on accessing care through non-voluntary routes (such as through a process of formal sectioning), as these require a different focus and research design (indeed, a greater justification for this thesis' specific approach will be given within the review of literature below, acknowledging that this encompasses only a portion of the total access to care that currently takes place). This study focuses on the seeking (or receipt) of care via a GP. Importantly, as I will expand upon below, seeking care via a GP *may* involve some level of coercion, as Pescosolido (1998) points out; it may be more useful to view this study as addressing the receipt of care through a GP, for people who do not enter care through involuntary routes. The reasons for this will now be more fully explained.

An examination of contemporary research pertaining to help-seeking in the field of mental health reveals concern at the high levels of attendance within primary care; Shaw and Woodward (2004) point out that based upon a community sample, over 20% of the community attends a consultation with their GP in relation to psychological distress, in any one year. There are arguments relating to the cause of this that I outline throughout this chapter, that provide competing explanations for such high numbers (or viewed from another perspective, such high 'incidence of disease'). Such arguments fall into two main camps: that there is an increase in the prevalence of mental illness, or that the term 'mental illness' has expanded to encompass difficulties that are not representative of true 'illness'. Despite these high figures of attendance, there is also concern that those treated within primary care represent the 'tip' of a 'clinical iceberg' (Pill *et al.* 2001, Hannay 1979); Pill *et al.* suggest that 'health services treat only the tip of the sum total of ill health' (Pill *et al.* 2001, p.212). There is therefore a significant level of care sought within the population, yet there is also a sentiment that there is a significant amount of untreated disorder remaining in the community.

Previous research related to help-seeking

This section will focus upon empirical research related to help-seeking. This will achieve the aim of providing insight into how help-seeking is currently viewed, how it has been researched in the past and some abiding problems within this body of work (what I later term 'the help-seeking problem'). This review addresses research into help-seeking relating to mental health difficulties in particular; later on in this section I will provide a brief summary of models that have been used to account for help-seeking and illness behaviour more generally (*i.e.* the broader field of health, as opposed to mental health in particular). This is to acknowledge awareness of the broader field of modelling illness behaviour in which this study is located, and to acknowledge the strengths and weaknesses of previous approaches and their suitability or otherwise in explaining 'the help-seeking problem'.

Help-seeking is studied in a variety of ways and from a variety of different perspectives. This includes *different disciplines* such as psychiatry, psychology, social psychology, sociology and anthropology; for *different*

outcomes such as to identify barriers, explain variation in usage between different demographics, understand how best to encourage more help-seeking amongst hard-to-reach groups (*i.e.* to bring help-seeking in line with what might be viewed as appropriate by professionals); and using *different approaches* such as examining the illness experience of people who have sought help, or understanding the networks surrounding help-seekers. The body of work is difficult to unify into a comprehensive or clear picture but I will point to some of the major themes so that the diversity and complexity is apparent, and an overall ‘help-seeking problem’ might be easier to discern.

‘Determinants’ and barriers

The most widely addressed topic in help-seeking literature engages with different ‘determinants’ of help-seeking; that is, factors that appear to correlate with higher levels of help-seeking, the inference being that these factors might *play a role* in whether one person is more likely to seek help than another. Much (but not all) research relating to determinants and barriers is carried out from a positivist standpoint, engaging with specific determinants that are likely to predict or explain patterns of help-seeking amongst diverse groups. Turning to *determinants* first, the most commonly-cited, strongest predictor of help-seeking is found to be ‘need’ or ‘severity’ (Bebbington *et al.* 2000b, Pescosolido and Boyer 1999, Bebbington *et al.* 2000a, Rickwood and Braithwaite 1994, Biddle *et al.* 2004), with co-morbidity playing a role in increasing likelihood of seeking help (Andrews *et al.* 2001b). However, this picture is by no means clear and there is some conflict between the different areas of research; different pieces of research present different pictures. Meltzer *et al.* (2003) suggest that *reluctance* to seek help *increases* with severity of symptoms, and Addington *et al.* (2002) argue that the probability of seeking help varies with diagnosis. Any relationship between severity and help-seeking is therefore far from clear, although there is gradual acceptance within the field that, frequently, those who need help most are most reluctant to seek it (Horwitz 1996, Bebbington *et al.* 2000b). Help-seeking is not necessarily an accurate indication of need, and research continues to try and address why a high prevalence of ‘low need’ individuals use services, whilst those with high need may remain outside of services (Horwitz 1996). Recent

interpretivist work (Biddle *et al.* 2007) points to a cycle of avoidance that seeks to normalise – that is, explain with reference to life events (see below for a fuller definition) – increasingly ‘severe’ levels of distress in an attempt to avoid the acknowledgment of ‘real distress’, showing that increased need does not necessarily meet with increased help-seeking, but providing some understanding of why.

Demographic and socio-economic variables are said to play a key role in mediating help-seeking; gender, ethnicity, age and education have been found to correlate with different patterns of help-seeking (Rhodes *et al.* 2006, Andrews *et al.* 2001b, Rabinowitz *et al.* 1999, Pescosolido and Boyer 1999, Vanheusden *et al.* 2009, Shaw *et al.* 1999, Horwitz 1996) with gender showing as one of the strongest correlates of mental health service use (Andrews *et al.* 2001b, Rabinowitz *et al.* 1999, Vanheusden *et al.* 2009, Horwitz 1996). However, this complicates the view that need is a strong predictor of service use; if gender is a strong predictor of help-seeking (and if need is indeed the strongest indicator), then it would follow that women (who have higher rates of help-seeking) have the greatest need for mental health services; this could be in line with arguments around social causation – that women have higher rates of distress arising from their different social roles and status compared to those of men (Busfield 1988). However, Bebbington *et al.* (2000b) showed that women were ‘70% more likely than men to contact their family doctor with a mental health problem, even after severity of illness was controlled’ (Bebbington *et al.* 2000b, p.1363). There is significant evidence that suggests women’s use of mental health services may be linked to other factors, such as greater willingness to talk about mental health issues (Vanheusden *et al.* 2009), greater attendance in primary care that may be linked to contraception and/or reproduction (Hunt *et al.* 2009, Hunt *et al.* 1999) (Mechanic (1978b) discusses women’s increased receipt of health care in general, derived from contact relating to childbirth and fertility), and the potential that the diagnostic classificatory system is biased towards viewing women’s emotional distress in more pathological terms compared to that of men (Rogers and Pilgrim 2005). As mentioned by Andrews *et al.* (2001b), educated women of child-bearing age are considered the only group to consult appropriately, and this would make sense in light of greater need to consult for issues related to fertility and

contraception *i.e.* it is their presence in medical care that is a pivotal factor in their help-seeking. Such an argument defies the simple explanations of either social causation or social construction, and can be related to discussions around the increased medicalisation of women's lives compared to those of men's (such as that presented by Conrad (2007)). Age is linked to different patterns of help-seeking, with low rates of help-seeking in the young and old, and higher levels in 24-54 year olds (Biddle *et al.* 2006, Biddle *et al.* 2004, Andrews *et al.* 2001b, Horwitz 1996). Researchers stress a high level of need amongst young people that is not aligned with help-seeking, indeed, appropriate help-seeking for young people is viewed as crucial by researchers who suggest that a significant proportion of mental health difficulties arise when people are young (Yap *et al.* 2012, Reavley *et al.* 2012, Wright *et al.* 2011). Pescosolido (2010) points out such complexity in relation to need and other determinants, and suggests that patterns relating to seeking help that show demographic differences between groups, are not readily explainable.

These examples of complexity within help-seeking statistics *i.e.* differential access to care that is not easily explained, suggest a need for caution in regards to simplistic explanations by virtue of demographic characteristics. The level of importance given to demographic and socio-economic factors varies from very important, to not significant (for example, Meltzer *et al.* 2003). Whilst many models include the interaction of different factors in multiple regression analysis, consensus remains at best considered as tentative patterns, with causal inferences remaining open to challenges. There is frequent evidence to suggest that certain groups (such as females) do seek help more frequently than others, but such patterns cannot be reduced to single factors and may be somewhat unrelated to need. The picture painted by such a body of research therefore suggests that whilst there are some differences in help-seeking between different groups of people, positivist and deterministic accounts are somewhat lacking in explaining why patterns are as they are. The need for research that unpicks some of these contradictions is therefore evident.

The help-seeking 'problem'

Specifically, what can be viewed as the 'help-seeking problem' is this: there are very high rates of help-seeking and the causes of this trend are unclear;

apparent trends within help-seeking figures, specifically that certain groups consult more frequently than others, cannot readily be explained by reference to need. There are groups that access care less readily than others, potentially culminating in more serious manifestations of distress if left untreated; there is also a high prevalence of 'low need' individuals who seek care. It is not yet fully understood why these observed differences are as they are, and there is potential importance in helping those who most need care in accessing it, whilst at the same time understanding why there are high levels of help-seeking elsewhere. It is within this specific quagmire that this study seeks to locate itself, in order to elucidate, if possible, some of the nuances of such observations. In addition, the study seeks to consider lay understanding, to assess whether it might play a role in increased levels of help-seeking amongst some individuals; this aspect is discussed in the section on lay understanding below.

Previous research related to help-seeking (continued)

It is important to mention at this stage that non-help-seeking is conceptualised in different ways in the literature, with the most notable forms being failure to consult a doctor, and failure to *disclose symptoms* to a doctor (but attendance at an appointment nonetheless). Non attendance applies to individuals who remain outside of medical care, whilst attendance (without disclosure) relates to a different phenomenon, that of individuals either somatising (Kessler *et al.* 1999, Weich *et al.* 1995) their distress (that is, presenting distress in the form of physical symptoms), or seeking help for physical consequences of distress. Reluctance to disclose symptoms has been found to be related to doctor—patient relationships (Brown *et al.* 2011), as well as factors such as short consultation times (Pill *et al.* 2001) that reflect institutional constraints, as well as cultural influences (Brown *et al.* 2011). For those who do not attend, similar research themes are put forward but with an additional difficulty, in that it is very difficult to research a group's behaviour when their behaviour by its very definition prevents them from being identified. Those who do not seek help at all are therefore the most sought-after group in this area of research, for a myriad of reasons, not least because literature indicates that a failure to seek help may lead to extended suffering (NICE

2011a) and potentially a worsening of psychological state that could culminate in entry into care via a more stigmatised and distressing route (such as via sectioning). Research relating to non-help-seeking therefore rarely captures the views of those who might be most reluctant to consult, despite the obvious benefits of understanding more about why this might happen. Research into help-seeking is therefore intimately related to non-help-seeking; they are two sides of the same coin.

The literature considers and questions the concept of *barriers* to seeking help, and this is a useful direction in which to now turn. Barriers prevent individuals from seeking care, and examples of such barriers fall mainly into the categories of structural and attitudinal; barriers are perceived as being rooted in either the individual or their wider societal structure, or both. Structural barriers comprise factors relating to the provision and receipt of care such as access, cost and availability, and such factors may reflect and intensify inequality (the ‘inverse care law’: ‘The availability of good medical care tends to vary inversely with the need for it in the population served’ (Tudor Hart 1971, p.405), discussed by Chew Graham *et al.* (2002) in relation to depression). The perceived importance of such barriers to care has declined in recent years, and whilst they are still viewed as affecting the receipt of care to some extent (Bebbington *et al.* 2000b), this is alongside attitudinal barriers whose role is considered as increasingly significant (Andrews *et al.* 2001b, Andrews *et al.* 2001a). Findings that suggest structural barriers such as cost and access no longer play a significant role in deterring individuals from seeking help (Horwitz 1996) support this (see Andrews *et al.* (2001b) in relation to health funding amongst developed countries). Mental health literacy (Jorm 2000) and related factors such as knowledge about treatment effects, are discussed in the section on lay understanding below, however these comprise one aspect of barriers to care that are perceived as related to individuals’ attitudes and understanding. Stigma is perceived as a significant barrier to the seeking of care (Link *et al.* 1997, Thornicroft 2006, Barney *et al.* 2009, Griffiths *et al.* 2011), although its perceived importance is tempered by other factors pertaining to attitudes, for example the suitability of help from GPs (Prior *et al.* 2003, Brown *et al.* 2011). A frequently reported barrier is in relation to beliefs, such as the belief that no one can help (Biddle *et al.* 2007,

Cape and McCulloch 1999). Indeed, Gask *et al.* (2003) point out that individuals who are depressed may have low expectations of care and may not expect a doctor to listen to them or be able to understand how they feel. They suggest that the experience of depression itself potentially hinders the likelihood that an individual might seek help: 'Patients with depression have particular needs that their illness makes them less likely to receive' (Gask *et al.* 2003, p.279). Interestingly, the suitability of help from GPs is discussed – including from the GP perspective – by Dowrick (2009), who challenges the utility of the concept of depression (including its status as an illness) for the management of distress. Brown *et al.* (2011) point out that a significant barrier to seeking formal help was a belief that a GP was not an appropriate person to consult in the event of emotional distress; this was because participants were deterred by a perceived lack of empathy, and by a poor existing relationship with their GP. Other beliefs that pose a potential barrier are that one should 'be able to cope' (Vanheusden *et al.* 2009), which usefully leads into the concept of 'normalisation'. The term 'normalisation', which can be used in relation to physical health problems as well as mental health problems, refers to the process of finding 'reasons' or explanations from within a person's life that explain and justify their 'symptoms', or changes in bodily experience. Blaxter (2010) provides a useful illustration that shows how a person's wider life might render 'normalising' explanations feasible:

For oneself, there is a common natural tendency to rationalize and normalize symptoms if it is at all possible. The possibility of normalization, and the form it takes, will depend on the pattern of life in a particular group. People who do heavy work may consider backache normal; people who work long hours may expect to be tired; many symptoms are unnecessarily ascribed to 'it's just old age'. If a symptom is not too disabling and a simple cause not in the category of illness can be found, it may be ignored. (Blaxter 2010, p.79)

Normalising symptoms is perceived as a barrier to seeking care, and also to detection within GP consultations (Kessler *et al.* 1999). Cultural variation may exist in the extent to which normalising occurs, and Brown *et al.* (2011)

suggest that cultural differences in illness perception (that affect whether normalisation takes place) might lead to different rates of GP consultation:

differences in illness perceptions could lead to differences in detection by GPs. For example, for black African as compared to white British women, certain patterns of illness perceptions could lead to mental health problems being 'normalized'... For instance, the attribution of depressive symptoms to changes in social circumstances may engender the belief that these symptoms are a part of life, not warranting GP consultation. (Brown *et al.* 2011, p.372)

Furnham *et al.* (2011) suggest that normalisation is likely to be exacerbated by low mental health literacy. Normalisation is frequently cited as a barrier to seeking appropriate help, although Biddle *et al.* (2007) usefully point out that normalisation should not necessarily always be considered a 'barrier':

The helpfulness of pathologising distress that patients are able to tackle within normalised frames of reference has been questioned from sociological and medical viewpoints. The COA [cycle of avoidance] reinforces the need to balance clinical and lay perspectives when attempting to determine an appropriate threshold. Further research will be needed to ... ascertain at what point non-help-seeking becomes problematic. (Biddle *et al.* 2007, p.999)

Biddle *et al.* (2007) suggest that the question of when distress should be pathologised is not easily solved and that lay understanding, which plays a role in determining normalisation, should also play a role in deciding a suitable level for 'clinical' threshold (I will address 'lay understanding' more thoroughly below). Thus, normalisation is not necessarily a harmful process and lay beliefs may sometimes lead to non-harmful outcomes if individuals are able to deal with their distress by themselves, as Heath (1999) suggests:

what evidence we do have suggests that the depression which is apparently missed by general practitioners [through patients normalising

their ‘symptoms’ in consultations] runs a relatively benign and self-limiting course. (Heath 1999, p.440)

So, normalisation, whilst frequently cited as a barrier to help-seeking, is itself a complex subject and is linked to a person’s wider life (*i.e.* what factors about their life might be used to explain ‘symptoms’), as well as a person’s lay understanding.

Having discussed ‘barriers’, and a shift from focusing upon structural barriers towards focusing upon attitudinal, I have acknowledged a shift towards considering beliefs as holding the key to non-help-seeking. Biddle *et al.*’s (2007) findings advise:

only a minority of those interviewed in this study described being impeded by such ‘barriers’. Avoidance of help and denial of illness due to the meanings attached to each were far more prominent, thus challenging the image created by the concept of barriers of ‘willing’ individuals constrained by structural obstacles. These findings suggest that the meanings attached to lay diagnoses and *also* to help-seeking should be central to understanding illness behaviour as drivers of action – not just ‘barriers’. Reducing such meanings to ‘values’ that can be quantified as ‘cultural barriers’ misrepresents their pervasive nature as belief systems that can shape the wider process of illness behaviour. (Biddle *et al.* 2007, p.1000, italics in original)

They call for a move away from the more traditional approach of examining barriers, towards placing beliefs and the meanings attached to lay diagnosis as central to help-seeking behaviour. This can be seen in recent research which focuses on consideration of how people conceptualise mental illness (Moth 2009, Mallinson and Popay 2009). This also forms a central part of this project. Prior *et al.* (2003) similarly suggest that lay diagnosis is central to help-seeking behaviour, as opposed to stigma. ‘Conceptualisation’ and lay understandings are addressed later on in this chapter. Wright *et al.* (2011) discuss the complexities associated with effective recognition (or labelling) of mental

health difficulties, and suggest that there are both benefits and costs associated with the use of appropriate labels:

The use of psychiatric labels to describe mental disorders is associated with effective help-seeking choices, and is promoted in community awareness initiatives designed to improve help-seeking. However these labels may also be coupled with stigmatizing beliefs and therefore inhibit help-seeking: lay mental health or non-specific labels may be less harmful. (Wright *et al.* 2011, p.498)

Thus, how people construe and conceptualise mental ill health is intrinsically linked to the likely outcomes of whether (and when) help is sought.

Viewing help-seeking as culturally located, as opposed to specifically being a 'function' of different individuals' demographic or other profiles, provides a more holistic conceptualisation of the topic that situates help-seeking at the centre of (and therefore influenced by) cultural processes. Help-seeking behaviour is viewed as influenced by wider structures (MacKian 2004, Pescosolido and Boyer 1999, Mechanic 2003) and Mechanic (2003) suggests that issues of policy also impact upon help-seeking. It is therefore necessary to clarify why 'structural barriers' (as mentioned above) are moving out of focus, yet the broader structural environment is viewed as influential. The 'structural barriers' discussed above refer to specific barriers that prevent individuals seeking care, with such barriers being investigated as unitary influences. The recent shift away from them indicates a move away from the reductionism of identifying specific barriers, towards considering the individual as part of a wider structure that constantly feeds back into an individual's decision making 'system'. Therefore, structure is viewed as playing a crucial role, but in a much more complex way; it may be more useful to consider 'structure' as the 'wider environment' in which help-seeking takes place, by *defining* and *delimiting* the options available to individuals *as well as the wider belief systems that exist*. Such an approach suggests that all aspects of an environment, from healthcare systems to the beliefs of individuals, exert influence over behaviour and in differing ways. The work of Pescosolido and Boyer (1999) that has been developed over the last two decades – specifically, their Network Episode

Model (NEM) – encompasses such an approach, and will be discussed more fully later in this chapter.

Previous approaches to illness behaviour

Pescosolido & Boyer (1999) usefully summarise previous attempts to model illness behaviour drawing from different levels of explanation – from individual beliefs through to structural provision of services. They observe that different models, which began with different aims – such as the socio-behavioural model’s focus on understanding use of services during periods of illness, and the Health Beliefs Model’s focus on the behaviour of ‘well’ people towards take-up of vaccines (these are both discussed in more detail below) – have coalesced towards including central components of other models, to create a more holistic picture. The overarching aim of each model may remain subtly different, but the gradual move towards inclusion of a more varied, wide ranging set of influences, from the micro to the macro level, reflects greater acknowledgment that decisions related to health behaviour are influenced by a range of factors from societal beliefs, healthcare systems and policies to individual beliefs and assessments (Andersen 1995). Before addressing this more ‘contextual’ approach, it is useful to provide a brief summary of previous models addressing help-seeking, so that some of the history of its study can be understood. Various models of illness behaviour have been proposed and it is useful to consider some critiques of previous models, so that potential vulnerabilities of illness behaviour are understood from the outset. I will therefore provide a brief summary of the more pivotal models.

Parsons’ concept of the ‘sick role’ (1951) defined the differing rights, responsibilities and norms of conduct conferred upon both patients and doctors, when medical help is sought. His work received criticism for lacking empirical support and was described instead as an ‘ideal type’ that lacks relevance to concepts used by social actors to explain conduct (Dingwall 1976). It also failed to account for cultural variation and inattention to power (Fahy and Smith 1999). In addition, its applicability to ‘mental illness’ was demonstrated to be lacking due to public conceptions of ‘responsibility for illness’, seeing individuals as at least partly to blame (Segall 1976). Whilst his sick role concept has been widely critiqued, Parsons nevertheless explicitly asserts a link

between cultural values and illness behaviour (Shilling 2002) and considered the moral dimension of illness as important.

Rosenstock's original health beliefs model (HBM), created in the 1960s, linked individual behaviour (in relation to preventative action) to beliefs relating to susceptibility, severity of illness and benefits of taking action (Rosenstock 2001). His research was carried out in response to government concern in relation to public take-up of vaccination programmes and of testing for asymptomatic illnesses (Rosenstock 2001), and as such was oriented towards the action of 'well' people in relation to potential illness. The model is criticised for lacking consideration of structural and cultural influences (Quah 2001) and for assuming that help-seeking is based upon 'rational choices' (Pescosolido *et al.* 1998).

Andersen's socio-behavioural model (SBM), developed in the late 1960s, suggests that an individual's use of services depends upon the following three variables: need, predisposing characteristics and enabling resources (Andersen 1995). Biddle *et al.* (2007) critique the model as measuring individual beliefs 'using proxy variables that assume individuals share beliefs by virtue of broad socio-demographic variables' (Biddle *et al.* 2007, p.984) and is focused on 'barriers' to care, as discussed earlier. Pescosolido *et al.* (1998) apply a similar criticism to that of Rosenstock's model, namely that the model assumes 'rational choice' and also that help-seeking is necessarily voluntary, which will be addressed later in this chapter.

Zola (1973) attempted to understand why people sought help at the time that they did, despite significant delays between onset of symptoms and the seeking of help. He developed a list of 'non physiological patterns of triggers' (Zola 1973, p.683) that provided explanations for help-seeking taking place when it did:

- (1) the occurrence of an interpersonal crisis;
- (2) the *perceived* interference with social or personal relations;
- (3) sanctioning;
- (4) the *perceived* interference with vocational or physical activity;
- and (5) a kind of temporalizing of symptomatology. (Zola 1973, p.683)

Zola also found differences in the significance of specific triggers to different ethnic groups within his study.

The theory of reasoned action (TRA) and theory of planned behaviour (TPB) are both models drawn from psychology that are used to account for the behaviour of individuals with reference to ‘careful consideration of available information’ (Conner and Norman 1996, p.121); the TPB was developed out of the TRA (Conner and Norman 1996). Pescosolido criticises the TRA as being inappropriate to help-seeking as it relates more to people engaging in *preventive* behaviour (Pescosolido 2010). Indeed, Pescosolido suggests that models that assume ‘rational’ action are not an appropriate account of many people’s haphazard (and potentially non-voluntary) journey into care (Pescosolido 1992, Pescosolido *et al.* 1998).

Pescosolido & Boyer’s (1999) revised Network Episode Model (NEM Phase II) includes potential influences that take into account a wide range of factors including individual beliefs, cultural context, nature of the illness event and organisational constraints. The model therefore links the structural to the individual, and models a *dynamic* process (see below) where there is no set course, but rather a series of interactions between different influencing aspects. Such a model is therefore useful in illustrating that help-seeking is complex and ‘understood and managed through social interaction’ (Biddle *et al.* 2007, p.184). It is influenced by structural factors in varying ways, although Biddle *et al.* (2007) also suggest that the model is deterministic. A later revision of the model, NEM Phase III (Pescosolido 2011), brings an individual’s biology into focus in addition to their context, and Pescosolido suggests that such a model moves forward from the previous version – which focused on the *consequences* of illness – by including *causation* as well. She suggests that such a move allows for the entirety of an individual’s life to be considered as both affecting their mental health and also the pathways towards care that they might travel.

Biddle *et al.*’s (2007) ‘cycle of avoidance’ reflects an interpretivist engagement with how young people conceptualise ‘mental illness’ (in itself, and in relation to their distress), and demonstrates a cycle of interpretation of ‘symptoms’ whereby the threshold of what they consider to be ‘real distress’ is continually pushed beyond their current experience until circumstances render this no longer feasible (or they ‘recover’ naturally). The model makes use of a

dynamic approach (see below) and simultaneously explains help-seeking and non-help-seeking, albeit help-seeking remains couched in terms of individual choice as opposed to non-voluntary action that may also occur. Their work is used to understand the behaviour of young people, a specific group with low consultation rates, however the relevance of this cycle to other groups is a point of interest.

Recent research considers far more factors than simple correlates or determinants, such as the work of Biddle *et al.* (2007) and Pescosolido & Boyer (1999), who create *dynamic* models of help-seeking and view it as a process with various influencing factors and no clear pathway that can be reduced to ‘stages’; it was from this perspective that this project was undertaken. Whilst older models of help-seeking behaviour (such as the HBM and the socio-behavioural model) model a process involving stages that individuals pass through, newer models depict help-seeking as something that is inherently related to the wider cultural environment (such as the NEM and COA) and cannot be reduced to simple ‘stages’. The term *dynamic* refers to interactive processes between individuals’ belief systems, their inner experience and their wider environment, referring to an ongoing *journey* (as opposed to one point in time). Such dynamism refers specifically to *movement between*, and paints an interactive relationship between the individual and their wider environment; such journeys involve interpretation and reinterpretation, and repetitive cycles and shifting boundaries, that are unlikely to be homogenous and cannot be reduced to a set of stages, barriers or indeed a set of inputs. Pescosolido & Boyer (1999) point to such interaction:

This link between the day to day lives of individuals and their interactions in the community or the treatment system cannot be ignored. Such interactions shape how individuals who may need care – as well as those who provide care – view mental health problems, how they embrace or scorn what the treatment system offers, and whether they are encouraged or dissuaded to receive or provide care. (Pescosolido and Boyer 1999, p.410)

Having considered some of the different ways that illness action (and to some extent, help-seeking) has been researched, it is now useful to return to a reflection of developments that have taken place in understanding the *contextual* nature of help-seeking. Social networks are seen as affecting an individual's likelihood of coming into care, and provide one perspective into the way a person's context might affect care-seeking. . 's (1977) early study provides insight into the ways that different types of kin networks impacted upon individual's timing and likelihood of entering psychiatric care; his study of social networks was based upon Mitchell's (1969) definition of social network as a:

specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole may be used to interpret the social behavior of the persons involved (Horwitz 1977, p.87, citing Mitchell (1969))

Horwitz's study assessed the *structure* and *content* of networks, in terms of their closeness, the number of people contained within them, and the strength of those relationships. He argued that strong networks provided support to individuals but that this may culminate in delayed help-seeking (Horwitz 1977) whilst close friends and family attempt to (and may succeed) provide support; this was intensified if that network was also 'closed', that is, containing a smaller number of people who are closely linked (Horwitz 1977). The more 'open' a person's network (that is, with a greater range of members, with less close ties), the more likely they are to receive signposting towards psychiatric care, and to seek care more quickly (Horwitz 1977). More recent work by Pescosolido *et al.* (1998) found that respondents with closer social networks were more likely to report being coerced into seeking care. Thus, the types of networks surrounding an individual may impact upon the manner and timing with which they seek care. A different perspective relating to the networks around an individual is the concept of 'social capital'. Social capital was originally defined by Coleman (1988) and was then adapted and developed by Putnam (1995), who defined it thus:

“social capital” refers to features of social organization, such as networks, norms, and trust, that facilitate coordination and cooperation for mutual benefit. (Putnam 1995, p.67)

De Silva *et al.* (2005) provide a fuller definition for within the health sciences that is based upon Putnam’s early work:

The most accessible definition of social capital used in the health sciences originates with Putnam. He states that social capital consists of five principal characteristics, namely: (1) community networks, voluntary, state, personal networks, and density; (2) civic engagement, participation, and use of civic networks; (3) local civic identity—sense of belonging, solidarity, and equality with other members; (4) reciprocity and norms of cooperation, a sense of obligation to help others, and confidence in return of assistance; (5) trust in the community. (De Silva *et al.* 2005, p.619)

The concept is used to analyse different aspects of an individual’s networks and how such networks impact upon an individual’s connection to their wider community and its associated resources (as well as the type of resources that might be available). The concept of social capital is used to explain health inequalities (Marmot 2010) and is also used in the study of mental ill health (De Silva *et al.* 2005, McKenzie *et al.* 2002, Song 2011), explaining differences in rates of prevalence according to social capital. De Silva *et al.* (2005) point out that the importance of the concept is recognised by the UK government and features in recent mental health policy. Social capital can be seen as having positive and negative consequences (that is, social capital can impact on a person in a positive, or a negative way (Vassilev *et al.* 2011)), and has been used alongside the concept of social networks ‘as a way of demonstrating the existence of an important link between health and social contexts’ (Vassilev *et al.* 2011, p.13). There is some evidence to suggest that social capital can impact upon access to healthcare in relation to *physical* health (Choi 2009, Hendryx *et al.* 2002), showing workings in a similar way to those described by Horwitz (1977) above. In relation to access to mental health

care, Pescosolido (2011) focuses upon the different ways that *social networks* (as opposed to social capital) can impact upon access to healthcare:

Social networks ... can be flat or hierarchical, facilitating or restricting access to resources, including treatment. Further, they hold important content. Interaction in social networks creates cultures of information (*e.g.*, where one can get help for mental health problems), beliefs (*e.g.*, what others, providers or friends, say causes mental illness), and action scripts (*e.g.*, whether or not to seek formal care, what treatment regimes are suggested, and whether or not one should follow provider's recommendations). Network cultures can be parochial or cosmopolitan; that is, they may support modern medicine views or reject them in favor of other systems of healing (*e.g.*, traditional medicine, religion). (Pescosolido 2011, p.514)

Pescosolido suggests that the effect of networks in shaping an individual's eventual pathway to care is so strong, and also potentially idiosyncratic, that understanding it can 'help to explain inconsistencies in the mental health services literature that frustrated researchers for almost four decades.' (Pescosolido 2011, p.521). She argues that the contemporary recognition of the importance of networks that is becoming recognised from a multi-disciplinary perspective, reflects the pervasive nature of their role (Pescosolido 2011).

Dingwall (1976) pointed towards the importance of understanding an individual's action as inherently rational to the individual; he suggests that illness action (which here, encompasses the same as 'illness behaviour') reflects the outcome of an individual's interpretation of their illness:

Illness action is the outcome of continuing efforts on the part of the sick person, and those with whom he associates, to make sense of what is going on in the light of the knowledge, resources and motivations available to them. (Dingwall 1976, p.121)

Dingwall (1976) critiques behaviourist models that exclude individual purposes from their investigations; rather, he suggests that help-seeking should be

viewed as a form of social action. However, this perspective implies that action is necessarily purposeful, and does not account for the experience of those who are coerced into seeking help. Pescosolido (1992) considers the notion that individuals' actions are necessarily purposive and later argued that 'rational' action does not reflect the experience of many people's movement towards care; Pescosolido *et al.* (1998) argue that many models inappropriately assume that service utilisation is the result of active help-seeking, and suggest that coercion and 'muddling through' (Pescosolido *et al.* 1998, p.275) more accurately describe the passage for a proportion of individuals. It is therefore necessary to remain vigilant of definitions of help-seeking that infer rational choice, as this does not appear to be the case with a significant number of people who attend (Pescosolido 1992, Pescosolido 2010). There is therefore some considerable difficulty in creating a model that accounts for the behaviour of actors, given that there is such variety within the body of people who seek (and do not seek) help; indeed this notion of a grand narrative is at odds with an interpretivist framework. This therefore points to an inherent difficulty within a study of help-seeking; it is unlikely to be possible to create explanations for behaviour that account for the actions of individuals who come from diverse aspects of society and face differing experiences and needs. This stands in addition to the difficulty of providing an explanation that takes into account factors from the micro to the macro; any model will inherently have weaknesses.

A study of 'conceptualisation', as mentioned earlier, is a recent shift in the focus of interest (Biddle *et al.* 2007, Mallinson and Popay 2009, Moth 2009) that provides a different way of understanding links between conceptualisation and help-seeking (and subsequent engagement with treatment (Mallinson and Popay 2009)). However, as noted above in relation to previous models, it is necessary to exercise caution in considering what any approach leaves out. Indeed, caution should be exercised in assuming that illness behaviour is indeed an appropriate framework with which to view a person's behaviour during periods of what might be defined as 'illness'; whilst researchers and health professionals might consider it as such, individuals might interpret their experiences very differently. Pescosolido & Boyer (1999) point to the

importance of conceptualisation and argue that this very usefully points to the fragility of viewing action as necessarily 'illness' behaviour:

the nature of encounters people have in their day to day lives help to provide meaning to the symptoms of illness. If individuals see mental health problems as crises of faith, as bad marriages, or as any of a number of other things besides illness, they may consult faith healers, spiritualists, the clergy, or other people... If they, or others around them, see the problem as "bad behaviour" rather than illness, then they might seek out police and lawyers. (Pescosolido and Boyer 1999, p.408)

This is a crucial insight into the nature of illness behaviour; that what a doctor (or other person) might consider to be illness may well not be considered so by the individual, and this is likely to have a direct impact upon their choice of action. Rather than providing a clear way of understanding help-seeking, I have demonstrated that theories that seek to understand help-seeking shed light on a subject that cannot readily be separated into discrete and measurable influences. I will now turn to the literature relating to lay understanding, so that any potential relationship between the two phenomena can be more clearly outlined.

Lay understanding

Lay understanding, as a topic, is both important and problematic. I will begin with a discussion of its importance, before addressing its limitations, so that the relevance of its continued study is understood. This will then be followed with a review of empirical research into lay understanding around mental health. The terms 'lay knowledge', 'lay understanding' and 'lay views' will be used interchangeably, in order to minimise repetition for the reader; the terms will be viewed as interchangeable for the purposes of this study.

Lay understanding in relation to health (here I am referring to the broad area of health, before addressing mental health specifically) is viewed as important for a number of reasons, but the main reason in relation to this study is that lay understanding is held as playing a role in whether ill health is brought to the attention of medical professionals. Olafsdottir and Pescosolido (2011) point out the importance of lay understanding:

Lay diagnoses matter for at least three reasons. First, from a medical and public health perspective, when lay diagnoses do not align with expert ones, the failure to seek healthcare can lead to long delays which, in turn, produce prolonged suffering, higher costs to individuals and societies, and even premature death. Lay diagnoses hold the potential to impact diagnostic categories themselves. Second, from an indigenous system perspective, lay diagnoses lead to behaviors which are rarely lifethreatening and can alleviate symptoms, reduce the duration of illness, and activate positive health behaviors. Third, from a theoretical point of view, the public response to scenarios that match formal diagnoses of allopathic medical systems tells us about the medicalization of culture, the nature of support for formal and informal healing options, and cleavages in the adoption of dominant, Western belief systems. The fact remains that people rely most often on their own or others' assessments of the onset of symptoms. Based on those evaluations, they rely on community resources before ever considering whether they will seek out formal medical care. As such, lay diagnoses reveal important information about cultural systems, particularly judgments on cultural beliefs regarding social problems and the potential response pathways that those cultural beliefs lay out. (Olafsdottir and Pescosolido 2011, p.936)

Without individuals bringing illnesses to the attention of the medical profession, illnesses remain untreated and may potentially worsen; from the perspective of health policy-makers, there is importance attached to members of the public being able to recognise signs of illness and act accordingly so that treatment can be given in a timely fashion. Lay understanding has much broader implications than this, for example its effect upon treatment compliance and whether individuals accept or reject a medical professional's diagnosis (as well as a broader discussion around medicalisation, which is discussed in more detail below); however, from a health policy perspective, great importance is attached to individuals being able to recognise signs of illness and *act accordingly*. Lay understanding is said to play an important role in the help-seeking process, as Olafsdottir and Pescosolido (2011) point out:

All major theories on help-seeking, service utilization, and health behavior change begin with a clearly specified role for the lay construction of illness. (Olafsdottir and Pescosolido 2011, p.930)

Furnham (1988) suggests that individuals interpret experiences using the framework of their lay belief systems, and seek explanations from within belief systems to explain events if possible; this leaves open the possibility of non-medical explanations, according to a person's own belief systems. This will be discussed in more detail below, when considering research that addresses lay understanding around mental health in particular.

Literature around lay understanding covers many diverse aspects of health and illness (over and above the specific types of 'conditions' and illnesses that are researched), for example the nature of lay understanding, and the ways in which understanding around health may be patterned according to different demographic characteristics. Lay understanding is also associated with health behaviour, a concept that is different to illness behaviour (health behaviour refers to what activities individuals engage in, such as smoking, that may have a negative or positive impact upon their physical health, and is not a focus of this study; a definition of illness behaviour was given earlier in this chapter). A study of the literature relating to lay views around health (focusing on physical health to begin with) reveals that lay views may vary depending upon variables such as gender, age, social class and educational attainment (Blaxter 1990, Herzlich 1973), with differing emphasis depending upon how a person's health might affect their broader life. For example, Blaxter (1990) discusses the salience of 'functionality' in relation to older respondents in her study, and the importance of physical fitness and vitality to the younger respondents in particular. In the broader field of research relating to lay views around health and illness, Bury (1997) discusses the *nature* of lay views and their 'loosely organised and fluid character' (Bury 1997, p.31), and it is understood that lay views around health and illness are not constant, but change over time (Blaxter 2010, Furnham 1988, Williams and Healy 2001). In addition, lay views need not contain internal consistency, *i.e.* they may contain contradiction, or draw from more than one paradigm at once, and without this being perceived as a problem to the individual (Bury 1997, Furnham 1988).

As mentioned above, there is relevance in research into lay understanding, because it is perceived to play a role in a person's likelihood of seeking help at any one point in time; it is therefore necessary to proceed with caution when researching lay knowledge, because an individual's lay knowledge is not likely to be a constant, nor will it necessarily be internally consistent. Both Blaxter (2010) and Bury (1997) point out the need for caution when researchers attempt to predict behaviour based upon lay understanding. Even though writers discuss the implications of individuals holding views from one particular paradigm as opposed to another (for example, Sayce (2000) discusses the implications of how drawing from different explanatory models in relation to mental health holds significantly different implications for individuals in regards to individual responsibility, treatment and stigma), Bury (1997) cautions against inferring behaviour based upon understanding. He argues that views cannot be placed within a 'simple explanatory framework' (Bury 1997, p.32). Research that seeks to explore the relationship between help-seeking and lay understanding must bear in mind this caution. Research into lay understanding can also be carried out in different ways, for example, Furnham (1988) suggests examining lay theories in terms of 'content' (that is, examining the content of lay understanding and considering how these fit into broader world views such as 'conservatism' or 'just world') and 'process' (which relates to how people make sense of things, how they assimilate information and form a conclusion).

Lay knowledge is a problematic term (I will discuss its problematic nature below), but is used to describe the knowledge and understanding that people have around the subject of health, who are not health (or mental health) professionals. The term 'lay knowledge' has been favoured by Pilgrim and Rogers (1997) in particular, replacing the term 'lay beliefs':

The term *lay knowledge* is preferred here because of its attendant connotations of validity, rather than *belief*, which is the preferred term of most current health psychologists and is also present in the earlier work of sociologists of health and illness. (Pilgrim and Rogers 1997, p.39, emphasis in original)

As Pilgrim and Rogers suggest, the term ‘knowledge’ confers greater status than the term ‘belief’, and this shift is recognised in the terminology used in this thesis. Busfield (2011) uses the term ‘lay ideas’ as an alternative, and so it is important to recognise that there are variants, some of which contain specific connotations. It should be noted that the term ‘lay beliefs’ is still used by some researchers, for example the work of Adrian Furnham who is discussed later in this section; the term ‘lay beliefs’ may therefore be used if directly quoting such work. Lay knowledge has frequently been viewed in terms of its ‘inferiority’ to, and juxtaposition against, ‘professional’ knowledge (since the early work of Freidson (1970) and Dingwall (1976)). When viewed in such a way, lay knowledge has been studied with the intention of finding out its ‘deficiencies’, in order to help bring lay views more into line with professionals’; Pilgrim and Rogers (1997) criticise the work of Adrian Furnham (whose work is considered in this review) for this in particular. Pill et al (2001) provide an additional illustration of this assumption, in relation to common mental health problems:

As with many other medical specialities, the perception is that any discrepancy between professional and lay attitudes and beliefs about symptoms, diseases, appropriate behaviour by the sufferer and treatment is generally due to ignorance, prejudice and misunderstanding on the part of the patient. (Pill *et al.* 2001, p.209)

Whether viewed in terms of a ‘deficiency’ of knowledge, or in less subjugating terms, the gap between professional and public knowledge is frequently viewed as a hindrance towards effective treatment (Angermeyer and Matschinger 1996a, Jorm *et al.* 1997b), and Jorm’s (2000) term of ‘mental health literacy’ is frequently discussed. However, Pilgrim and Rogers (1997) point out the potential legitimacy of lay knowledge whilst discussing Furnham’s subjugation of lay beliefs in contrast to those of professionals:

This is not to say that lay knowledge necessarily should be privileged over expert knowledge. But it is to acknowledge that sometimes lay people develop forms of knowledge which are legitimate and

occasionally even superior to the current state of professional knowledge.
(Pilgrim and Rogers 1997, p.39)

Although it has been found that lay knowledge has shaped professional knowledge in some areas (Pilgrim and Rogers 1997), lay knowledge is rarely given the status that has been recommended (for example by Dingwall (1976)). Popay and Williams (1996) suggest that this is achieved to a limited extent in research within the social sciences.

The concept of laity has been problematised (as mentioned above), in relation to whether 'lay understanding' actually exists in a form that can be researched (Shaw 2002). Blaxter (2010) points out that the term has evolved to the point where it may need to change all together:

Boundaries have now become blurred: professional knowledge now includes much of the 'alternative'. Lay knowledge rests on both tradition and medical science. Indeed, it has been argued that, just as it is not practical to oppose illness and disease, so the label 'lay' concepts, though common as a shorthand, is not useful in modern Western societies, where lay accounts are usually filtered through internalized professional accounts. Lay beliefs can be better defined as commonsense understandings and personal experience, imbued with professional rationalizations. (Blaxter 2010, pp50-51)

The concept of 'laity' is clearly one that is problematic, and it is imperative that researchers bear in mind the likelihood of professionalised views (as well as views drawn from alternative frameworks) being present in varying degrees. This is especially the case if 'lay' participants have been in receipt of a medical diagnosis in relation to mental ill health, and it is useful to illustrate this point by drawing upon some research from 2001. Kangas' (2001) study aimed to consider how the respondents in her sample viewed depression (all participants self-reporting as being depressed); Kangas found that their conceptualisations around depression, specifically its etiology, drew from professional discourses such as psychology, psychotherapy and psychiatry. The project found that

respondents fell into three categories depending upon when the participant viewed the causes of their depression as occurring, as follows:

Three narrative types following a distinctive storyline were detectable: first a storyline based on the shortcomings or deprivations of early development, concentrating on childhood and adolescence experiences. A second storyline, focused on excessive demands and role conflicts, presented as causes of work-related burnout, that developed into or already contained traits of depression. A third storyline was formed along precipitating and symptom provoking factors in adulthood, outlining a story of hardships, losses and severe life events, which were reacted upon with depression. (Kangas 2001, p.80).

Kangas linked these narratives to professional discourses within the field of mental health. However, Shaw (2002) questioned the validity of the findings as representing 'lay' understanding, given that the respondents had mostly had some form of therapeutic intervention and had therefore adopted and internalised the viewpoint of the professionals with whom they have had contact (Shaw 2002). Shaw problematises the notion of 'lay understanding' suggesting that

lay beliefs are extremely difficult, if not impossible, to study because they are tied up with the certainty of diagnosis and the legitimacy that is afforded by taking on medical rationality. Moreover, 'commonsense' views are themselves based upon understandings within expert paradigms. (Shaw 2002, p.287)

Shaw argued that the participants in Kangas' (2001) study had taken on 'medical rationality' and that due to their status as having been 'diagnosed', any 'laity' had been lost. Moreover, he goes on to suggest that all participants, whether they have received a diagnosis or not, still base their views on what they understand of existing 'expert paradigms' within lay discourse. This problematises the idea of laity, suggesting that even those who have not been in contact with a health or mental health professional are still likely to draw from

ideas and concepts that are taken from professional discourse. Shaw points out that ‘people ‘pre-professionalize’ their thinking in the lead up to an encounter with a professional’ (Shaw 2002, p.292) drawing from the work of De Swaan (1990) (whose work is summarised below in the section on ‘medicalisation’). It is therefore important to acknowledge that when discussing lay understanding, different professional paradigms may be evident, to differing degrees, and those who have received some form of professional care (and diagnosis) are particularly likely to have taken on some measure of that professional rationality; this was borne in mind in the design of this study, as discussed in chapter 3 (methodology). Shaw suggests:

Those researching accounts of illness need to be particularly sensitive to the understandings displayed by their respondents during interviews and the extent to which these may have been influenced by discourses within medicine (or other expert health knowledge systems) or their interaction with professionals concerned with health. (Shaw 2002, p.297)

However, despite the difficulty in accessing ‘laity’ in any meaningful sense, the literature nonetheless points towards the importance of people’s understanding (or knowledge) in relation to different health issues. The underlying rationale of research into lay understanding therefore remains, albeit with an acknowledgement that the term ‘lay’ may not be very apt; there will most likely be views drawn from professional paradigms (as well as alternative paradigms) present. With this caveat in mind, I will now provide a broad summary of empirical work into lay understanding around mental health.

Previous research into lay understanding around mental health

The literature that is reviewed here addresses lay understanding in relation to a range of mental health problems, not just those classed as ‘common mental disorders’. It is also important to have an awareness of lay understanding around different mental health difficulties, so that it is possible to draw parallels with the study data if appropriate. In addition, it may be that people’s understanding about certain mental health difficulties is *in relation to* other difficulties. Lay understanding may not necessarily differentiate between

different mental health difficulties in the same way that researchers do. For this reason, the literature reviewed encompasses a greater range of mental health difficulties than those referred to as common mental health disorders.

When examining help-seeking research, there is frequent reference to a link between lay understanding and help-seeking, as mentioned above, drawing from diverse work that spans a range of disciplines, including sociology (such as the earlier work of Dingwall (1976)), psychiatry (such as the work of Angermeyer (1999)) and public health (such as the work of Jorm (1997b)). Some literature that is relevant to lay understanding will be discussed in the help-seeking section; because the two areas are related, much research addresses both areas. I have attempted to minimise repetition between the two sections (help-seeking above, and this section on lay understanding), though some repetition will be unavoidable.

As mentioned in the introduction to this section on lay understanding, lay knowledge is viewed as important because it plays a role in helping people to understand and interpret symptoms, and then seek appropriate care if necessary. Underpinning this assertion is an assumption that the framework that an individual applies to understand a certain phenomena (such as medicine or religion) will affect how they choose to address it (such as seek medical help, or the help of a religious elder), as mentioned by Pescosolido and Boyer (1999) in the help-seeking section above. For this reason, there is importance attached to understanding what lay views are held around the nature of mental health problems, such as causation and amelioration, so that behaviour can be understood (and potentially influenced) as part of a wider conceptual schema; this area encompasses a significant body of work in the study of lay understanding.

Lay understanding has been the subject of much positivist investigation, including work unrelated to help-seeking (for example topics such as stigma and acceptance of people with mental health difficulties (Link *et al.* 1999, Angermeyer and Matschinger 1996b, Klassen 2009)). There is significant research into public understanding around causation (Angermeyer and Matschinger 1996a, Jorm *et al.* 1997a, Furnham and Chan 2004); lay understanding tends to focus around either psychosocial or biological causes, with variation depending upon the type of diagnosis in question, for example,

depression is frequently viewed as caused by social factors, whereas schizophrenia is viewed more as caused by biological factors (Furnham 2009). Where causes are viewed as psychosocial, non-medical interventions are generally preferred, such as psychotherapy or talking with family and friends (Reavley *et al.* 2012, Furnham 2009, Lauber *et al.* 2003); where causes are viewed as biological, medication may be viewed as the most appropriate option (Sisley *et al.* 2011, Angermeyer *et al.* 2011, Furnham 2009, Lauber *et al.* 2001) (although this may be in addition to psychological therapies). Prins *et al.* (2008) suggest that patients who have received a diagnosis and treatment for depression are more likely to view causation as biological, and more likely to perceive value in medication, than people who have not experienced (or received a diagnosis of) depression. Hogg's (2011) study showed that many people did not consider depression to be in the realm of medicine, but rather as a social phenomena that is part of the human condition; Pill *et al.*'s (2001) study found a similar reluctance to label emotional problems as 'illnesses'.

Depression may therefore be viewed by some as outside of the paradigm of medicine, and not amenable to 'treatment' of any form, but rather to be improved or relieved by a person's social world alone (Hogg 2011, Brown *et al.* 2011), addressing 'the root of a person's problems' (Pill *et al.* 2001, p.217)). Whether viewed within a medical framework or outside of it, the term depression is viewed as having predominantly social (or psychosocial) causes (Prior *et al.* 2003, Schomerus *et al.* 2006). It is worth, however, noting Bloor's (1983) caution, that when discussing depression (and Jorm and Reavley (2012) extend this to the term 'mental illness'), the views of the public may differ from those of professionals about what is encompassed by such terms, and what is actually being discussed. Klineberg *et al.*'s (2011) study (relating to identification of mental health problems as being separate to distress that is problematic) points out that amongst their target sample of young people, males from deprived backgrounds were the least likely to label a vignette of severe depression as a mental health problem and also least likely to advise seeking help. There were similar findings amongst females in their population; 'identification' and classification of difficulties is a central issue in the study of lay understanding. How individuals perceive the concept of 'mental health difficulties' varies between cultures (much of Furnham's work is in relation to

cultural differences, for example Furnham and Chan (2004)); the impact of cultural differences upon understanding (and help-seeking) is explored in the context of the UK between different communities (for example, the work of Brown *et al.* (2011) and Sisley *et al.* (2011)) and in relation to migrants (including refugees) outside of the UK (Maier and Straub 2011, Kokanovic *et al.* 2010). Recognition of a person's distress as a mental health problem may be a factor in the non-seeking of care, and recognition is affected by a variety of different factors.

In relation to treatment available via a GP, medication is frequently viewed in a negative light (Prior *et al.* 2003, Pill *et al.* 2001, Priest *et al.* 1996), indeed, Williams and Calnan (1996) note this tendency in relation to lay views about physical illness as well; psychotherapy and counselling are viewed rather positively (Reavley *et al.* 2012, Paykel *et al.* 1998). Paykel *et al.* (1998), in their study following the Defeat Depression Campaign, noted the following views in respect to GPs:

Two thirds of subjects would consult their GP if they suffered from depression, and this proportion was much higher than for any other kind of helper... A substantial proportion of respondents endorsed the view that people are embarrassed to consult the GP about depression or are afraid they will be regarded as unbalanced or neurotic. However an approximately equal proportion viewed GPs as being well trained to deal with depression. GPs were regarded by over half as simply giving pills. (Paykel *et al.* 1998, p.520)

The work of Pill *et al.* (2001) provided very useful insight into the views of lay participants in relation to services that might be available; their participants felt that GPs did not have sufficient time to listen to their problems, and may be able to offer little other than medication; Pill *et al.* argue that:

the reluctance of people to see their problems as requiring medical intervention has to be distinguished from their capacity to evaluate the services on offer. (Pill *et al.* 2001, p.217)

and conclude that ‘Patients are not necessarily irrational in their assessments of what is on offer.’ (Pill *et al.* 2001, p.217). Thus, views about the efficacy of treatment have to be separated from views about the availability and accessibility of treatment, and the process of consulting a GP; Brown *et al.*’s (2011) participants expressed difficulty in talking to their GP, due to a perceived lack of empathy, or a belief that their GP was not an appropriate person with whom to discuss emotional or psychological difficulties. This echoes the findings of Pill *et al.* (2001) who observed a similar reluctance:

To date, research has concentrated on exploring the perceived failure of GPs to recognise psychiatric disorder with less attention being paid to the reasons why patients may be reluctant to disclose symptoms to their GPs... It is clear that if patients were readier to discuss emotional problems with their GP this could dramatically increase the likelihood of recognition... in particular, those who “normalise” *i.e.* find common-sense explanations for their symptoms are less likely to be detected. (Pill *et al.* 2001, p.208)

This leads back to a related issue, which is that whilst some individuals may seek help whilst experiencing emotional distress, their GP may not necessarily recognise this, which is briefly discussed in the help-seeking section earlier in this chapter. Gask *et al.*’s (2003) study indicates that individuals who are depressed, as a consequence of their depression, may have low expectations of care and may not expect the doctor to listen to them or be able to understand how they feel. They suggest that the experience of depression itself interferes with the help-seeking process: ‘Patients with depression have particular needs that their illness makes them less likely to receive.’ (Gask *et al.* 2003, p.279). Their study also found that individual’s expectations around care varied according to previous experiences of the individuals and their close circles (Gask *et al.* 2003). Thus, according to Gask *et al.*’s research, the experience of depression itself might lower a person’s expectations as to the benefit of seeking help via a GP. Public understanding around the efficacy of treatment differs to that of professionals (Angermeyer and Matschinger 1996a, Jorm *et al.* 1997b). The issue of stigma permeates help-seeking and lay understanding, and

so has already been briefly discussed earlier; in relation to lay understanding in particular, Griffiths *et al.* (2011) found that stigmatising attitudes meant that individuals were more likely to prefer self-care as opposed to seeking formal help; there was a perception that depression was best dealt with alone. As a counterpoint, Brown *et al.*'s (2011) study found that only a minority of individuals who chose not to consult their GP cited stigma as a reason (this accounted for only 16% of their respondents). Stigma is discussed in greater detail in the help-seeking section above.

Lay understanding is therefore viewed as very important to the process of seeking help, and in determining the type of help to which individuals will be amenable, despite the changeable nature of lay knowledge and the multiple sources and experiences that continue to shape it (Lupton 1994). Pescosolido (2011) highlights the crucial role that social networks, in conjunction with lay referral networks, play in helping a person come into care, and in determining the *type* of care that is advised:

The structure of networks calibrated the “push” or amount of social influence, but only cultural context determined the direction of the trajectory, *i.e.* either toward or away from the formal medical system. When the push is great (*i.e.* in extended social networks) and beliefs held are in concert with modern scientific medical methods, the “lay referral system,” as Freidson (1970) called it, pushes individuals into care. A similar network structure with beliefs in opposition to modern medical care would exert the same amount of influence but would likely do so in the opposite direction. (Pescosolido 2011, p.521)

It is appropriate here to highlight the work of Freidson (1970) that is referred to by Pescosolido (2011) above. Freidson (1970) points towards the importance of the ‘lay referral system’ (Freidson 1970, p.290), which he argues plays a crucial role in an individual coming into care (as well as ascribing some form of diagnosis):

there is a great deal of data bearing on such topics as polio immunization, choosing a doctor and seeking psychotherapy that confirms the

importance of the social processes of seeking advice before, during, and even after one is struggling with a health problem. Such advice contains an implicit diagnosis of the problem. As important, it tends to constitute a referral to some agent or agency thought competent to deal with the problem, thereby moving the complainant toward care... In this sense, we may consider advice-seeking and advice-giving in health affairs among laymen to *organize the direction of behavior by referral* to one or another consultant. And so we can speak of a lay referral system, which is defined by (1) the particular culture or knowledge people have about health and health agents, and by (2) the interrelationships of the laymen from whom advice and referral are sought. (Freidson 1970, p.290, emphasis in original)

Freidson highlights the central role of the lay referral system in ascribing a diagnosis as well as shaping the direction of travel towards help, and he suggests that the structure and content of the lay referral system play a role in a person's likelihood of coming into care, similar to the work of Horwitz (1977) described in the help-seeking section above. Freidson (1970) also suggests that the process of interpreting and responding to illness is so rooted within an individual's community, that individualised models of decision making (and he cites Rosenstock's as an example) are not appropriate in accounting for rates of health service utilisation.

Despite the importance of lay understanding to the area of seeking help, Pill *et al.* point out that:

In relation to the common mental disorders, such as depression, it is very striking how few data there are on the perceptions, understanding and help seeking behaviour of people within the UK. (Pill *et al.* 2001, p.209)

It is in the context of this gap in research, that this study seeks to uncover more about lay understanding within the UK, and its relation to the help-seeking process.

This chapter will now turn to a discussion of the literature pertaining to medicalisation. This locates the study as potentially reflecting broader

processes pertaining to the *construction* of mental illness, and how shifting definitions might impact upon the prevalence of ‘illness’ as well as how people construe their own distress.

Medicalisation, and the shifting ways of understanding and categorising distress

I will now provide an outline of the concept of medicalisation, and its application to mental distress; there are various arguments that human emotions and behaviour are becoming increasingly medicalised and so it is important to provide an overview of the concept, its main implications, and how it may be feeding into current rates of help-seeking (and associated distress). Medicalisation is defined by Conrad (2007) as a process:

“Medicalization” describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders... The key to medicalization is definition. That is, a problem is defined in medical terms, described using medical language, understood through the adoption of a medical framework, or “treated” with a medical intervention... it is important to remember that medicalization describes a process. (Conrad 2007, pp4-5)

It is a process by which nonmedical problems come to be viewed within medical terms, and has been applied to a variety of different aspects of the human condition. It can be potentially applied to any aspect of bodily difference, change or function, as well as to behaviour, and Conrad provides the examples of male baldness, ageing and ‘sexual dysfunction’ (amongst others) that evidence changes in how life processes that were once viewed as normal (and simply as ‘difference’) are now viewed in more medical terms. The process of medicalisation is not ‘one way’, and problems can become demedicalised as well as medicalised; a notable example would be homosexuality (Conrad 2007), which was viewed as a psychiatric disorder (with associated ‘treatment’ (Rogers and Pilgrim 2005)) until a decline in this perspective from the 1970s onwards.

Whilst medicalisation can be applied to any issue within the realm of 'health' (and any aspect of the body) as mentioned above, its relevance to psychiatry (and behaviour, and the emotions) is most relevant for this thesis. Lupton (1997) draws upon Foucault's notion of the 'clinical gaze' (Foucault 2003 [1973]), and suggests that medicine's way of seeing (and understanding) our bodies shapes our own way of understanding and experiencing them; indeed, Lupton (1997) points towards Armstrong's (1994) oft-cited summation of how the clinical gaze has shaped the way people understand and perceive different bodily problems, based on a medical paradigm that is now employed for analysis:

A body analysed for humours contains humours; a body analysed for organs and tissues is constituted by organs and tissues; a body analysed for psychosocial functioning is a psychosocial object. (Armstrong 1994, p.25)

Indeed, Bury (1997) suggests that from a Foucauldian perspective, the body is now understood through the 'gaze' of medicine: "The body' does not really exist outside of the discourses (or medical 'gaze') that produce or 'fabricate' it." (Bury 1997, p.189).

The concept of medicalisation has been associated with social control as a way of defining and controlling characteristics that are deemed in some way undesirable, for example, Zola (1972) argued:

medicine is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law. It is becoming the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts. And these judgments are made, not in the name of virtue or legitimacy, but in the name of health. Moreover, this is not occurring through the political power physicians hold or can influence, but is largely an insidious and often undramatic phenomenon accomplished by 'medicalizing' much of daily living, by making

medicine and the labels 'healthy' and 'ill' *relevant* to an ever increasing part of human existence. (Zola 1972, p.487, emphasis in original)

For example, in addition to the example of homosexuality mentioned above, a now highly controversial 'disease' of 'drapetomania' was 'identified' in the mid 1800s during the years of slavery in the US (Rogers and Pilgrim 2005) and was used to explain the running away of slaves due to their discontent with their social roles; an appropriate 'treatment' was also 'identified' (Rogers and Pilgrim 2005). Medicalisation has not spread evenly across different demographics, for example it is argued that women's lives have been medicalised more than men's (Conrad 2007), an early example being the use of the term 'hysteria' to explain different aspects of women's behaviour (including 'rebelliousness' at the time of the Suffragette Movement (Showalter 1987)). Indeed, it has been argued that certain behaviours are defined as medical problems according to the expected behavioural norms of those in power, and this has led to accusations that psychiatric diagnostic categories are vulnerable to inherent sexism and racism (Rogers and Pilgrim 2005), as the profession of psychiatry remains predominantly populated by white males (Rogers and Pilgrim 2005).

Lupton (1997) points out that when medicalisation is discussed, it is generally from a perspective that views medicalisation negatively, and that critics tend to overlook the potential good that it can also do. It is therefore important to provide an overview of the positive and negative consequences of medicalisation so that both are acknowledged. Medicalisation has frequently been studied as representing the expansion of the power of the medical profession, although this argument is less focal now and it is accepted that medicalisation takes place based upon the actions of various different individuals and interest groups, such as pharmaceutical companies and patient interest groups (Conrad 2007). There are various potential gains for these groups; I will focus upon the gains for individuals and patient groups as gains for the medical profession have been well-discussed elsewhere (for example, beginning with the work of Friedson (1970)) as have associated gains for pharmaceutical companies, who benefit from the sale of pharmaceuticals (whose interests are acknowledged but are not central to the background of this

thesis). The remaining discussion, whilst including broader critiques of medicalisation, will focus in particular on the medicalisation of distress, and of behaviour, that come to be defined as within the field of mental health and illness.

For people who are experiencing difficulties, whether behavioural or emotional, the receipt of a medical diagnosis – as opposed to a different understanding of their inner experience or behaviour – may confer benefits: a diagnosis may culminate in access to resources, whether therapy, medication, psychological therapy, time away from work or potential welfare benefits. Indeed, Horwitz and Wakefield (2007) discuss the particular benefits associated to the receipt of a diagnosis for patients in the United States, where Managed Care may provide help for those diagnosed with an *illness* but not with difficulties arising from *life problems*. Diagnosis may also reduce blame on the individual for whatever is ‘wrong’ with them, providing a less stigmatising explanation than a label of ‘deviance’ (Conrad 2007, Busfield 2011); a biological explanation in particular has the potential to greatly reduce stigma (Sayce 2000), although this is not to imply that a biological explanation is stigma-free. A medical diagnosis might help alleviate blame not just for the individual who comes to be diagnosed, but also for those around them, most notably their families and parents (Sayce 2000), but also their social situation (as addressed below). Drawbacks of a biological explanation (for the individual) include the potential limitations that might then be placed upon future ‘wellness’ (*i.e.* their ‘illness’ is not necessarily something that can be overcome, but something that must be tolerated or adjusted to) (Conrad 2007), and potential reliance upon medication.

There are also strong critiques at a societal level, from writers such as Illich (1976), Conrad (2007) and Furedi (2004) who argue that by treating emotional problems as medical problems (or in the case of Furedi, as psychological problems), the structural factors that might be causing such problems are ignored and allowed to continue. Such critiques argue that the medicalisation of distress (and Illich (1976) would argue that medical treatment for many ‘illnesses’) provides an individualised solution (and individualised blame) for distress that may stem from problems within society such as racism and inequality, and that to treat the individual as ‘sick’ allows the harmful

societal conditions to continue. Indeed, Conrad (2007) suggests that locating the blame within the individual depoliticises their problems, and leaves the circumstances that created them untouched – thus ‘harmful’ societal structures are allowed to continue, and Illich (1976) argues that medicine actually serves to reinforce the reproduction of such a harmful environment by masking its true nature (that is, by continually locating the source of the ‘problem’ within the individual). Zola’s early work highlighted the same argument:

the labels health and illness are remarkable 'depoliticizers' of an issue. By locating the source and the treatment of problems in an individual, other levels of intervention are effectively closed. (Zola 1972, p.500)

There is also an argument that by viewing distress as something that requires professional intervention, members of society gradually become both less tolerant to distress, and also less skilled in being able to address it (*i.e.* their autonomy is reduced). Both Furedi (2004) and Illich (1976) argue that society’s way of making sense of certain suffering, and of beginning to view certain emotions or behaviours as ‘ill’ or ‘healthy’ changes the way in which such problems are addressed, and the resources that individuals call upon. Furedi (2004) particularly argues against the emergence of a ‘therapy culture’, and suggests that processes that were once viewed positively (namely, the private tolerance and acceptance of suffering, and of finding meaning within it) have now become viewed as undesirable and *avoidable*, and that culture no longer supports an approach of finding meaning within suffering (without therapeutic tools, that is). He also argues that a consequence of ‘therapy culture’ is that people define themselves by their vulnerability, instead of their potential, and that this shift has inherently weakened society’s collective emotional armoury; this would be an example of ‘counterproductivity’ that Illich warns is a potential consequence of medicalisation:

It [counterproductivity] exists whenever the use of an institution paradoxically takes away from society those things the institution was designed to provide. (Illich 1976, p.216)

Related to medicalisation, and to the idea that the existence of services changes the way individuals are equipped to deal with their own problems, is De Swaan's (1990) concept of proto-professionalisation; 'proto-professionalization' (De Swaan 1990, p.14) refers to the process of lay individuals coming to use professional terms to understand, describe and explain their experiences. It is by coming into contact with professionals that such terminology (and their associated paradigm) is conveyed and reproduced, and then from one layperson to another. He suggests:

the division of labour which has evolved among the helping professions also serves as a guideline in the everyday experience of laymen when putting their troubles into words and categorizing them; often there is hardly any other way to talk about these troubles than in the vocabulary that each profession has developed for its problem area and has conveyed to adjacent circles of laymen. (De Swaan 1990, p.101)

De Swaan argues that the way in which individuals respond to distress changes to one that accommodates the professional paradigm; he also argues that not only does this change how people understand and describe their problems, but that the very existence of a 'profession' creates a need for its services by shaping how individuals understand distress:

The profession [of psychotherapy] exerts an educating and proselytizing impact on the outside world. The external effect of professionalization is the formation of a clientele: the professionalization process operates in the surrounding society as proto-professionalization. And as people spend a greater part of their lives in circles where it is common practice to label one's everyday experience in accordance with the categories of psychotherapy and to put the basic concepts of the profession of psychotherapy into practice in everyday life, they will be the more likely to seek psychotherapeutic treatment and to benefit from it. (De Swaan 1990, p.101)

Indeed, De Swaan goes on to argue that the presence of a psychotherapeutic profession thus creates a need for psychotherapeutic help. He argues that this has become the *latest* way of framing and understanding ‘misery’:

People make troubles with themselves and with one another, and psychotherapists regard these troubles as psychiatric problems; as this professional concept spreads, people redefine their troubles as psychic problems suitable for treatment by the psychotherapist. But the troubles were already there. The service supply creates the demand, but it doesn’t create the misery... The entire area of troubled modes of experience and interaction has become the working terrain of the fairly new profession of psychotherapy, and in circles of people who are closely related to it, laymen have begun to recognize their troubles as psychic problems, whereas they were previously accustomed to speaking of bad behaviour and evil moods, of sin and of illness, of deliriums and rage, of bewitchment or destiny, of the usual imperfections of human existence – if they took note of these troubles and considered them worth discussing at all. Psychotherapy did not exist yet, and psychic problems were not recognised or experienced as such, but in many different ways. (De Swaan 1990, pp100-101)

De Swaan sets out a compelling argument that the presence of psychotherapy (in his example) is changing the explanatory arsenal upon which individuals might rely, in order to explain aspects of human behaviour that have been explained differently in the past (if indeed any explanation was necessary). Indeed, his argument relates current understanding to a historically-specific (and therefore historically unique) way of interpreting inner experiences. De Swaan’s argument implies similar to that of Furedi’s (2004), in that he suggests that individuals cease to rely upon their own resources in dealing with distress, and instead turn to – and indeed *need* – the help of professionals. These latter consequences of medicalisation provide potential alternative explanations for high recorded levels of distress (and high levels of help-seeking), and locate the ‘problem’ in a shift in how distress is perceived, tolerated and responded to. It is therefore important to bear these critiques in mind as an explanation for

the current high levels of distress (that culminate in a diagnosis of a common mental health disorder) that are being responded to within primary care; these are potential alternatives to ideas around social causation, that is, an increase in the factors that *lead* to mental distress.

An alternative explanation, that sits alongside these critiques and is related to medicalisation, can be found in the work of Horwitz and Wakefield (2007) who argue that there has been a shift in how ‘illness’ is diagnosed and also in how it is measured in community surveys. Horwitz and Wakefield provide a good critique of the figures themselves, that is, the surveys that suggest that there is an increase in the prevalence of mental illness; the surveys used include various community surveys from the 1980s onwards, as well as World Health Organisation (WHO) survey from 2004 (see Demyttenaere *et al.* (2004)). Horwitz and Wakefield (2007) suggest that rather than a particular increase in the prevalence of psychological distress in the population, there has instead been a shift in the process of diagnosis, that occurred when the need for an understanding of ‘context’ was removed from the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition (DSM III). As a result of this, they argue that ‘extreme sadness’ – that may be justifiable when viewed in context – is becoming redefined as a mental health problem and is leading to increased diagnosis and treatment of problems that are not actually true ‘mental illnesses’ (as defined by the authors). In addition, they argue that the figures reported for the general population are not representative of the true level of disorder, as community surveys are carried out with a similar disregard for context, and also without appropriate professionals to assess behaviour and identify pathology in behaviour *patterns*. Their argument therefore suggests that it is the classification and measurement of mental illness that has changed, not its prevalence, and that this has led to the medicalising of normal sadness.

There are other analyses relating to medicalisation (not specifically of distress, but such arguments may be transposed to the field of mental health) that locate it as part of an increased demand for medical intervention in the face of pain, distress and/or physical difference. These analyses draw upon cultural shifts that affect how individuals relate to their bodies, and the role that consumerism plays in increased consumption of medical treatment (Bury 1997, Featherstone *et al.* 1991). Shaw and Woodward (2004) argue that ‘high rates of

medicalisation are actually indicative of systemic problems in western society' (Shaw and Woodward 2004, p.128) which they link to a decline in the traditional mechanism of support – the community:

Community is where individuals are recognised and their individuality affirmed. Community is also the place of support mechanisms. The relevance of the traditional anchors and support mechanisms of community – the family, neighbourhood and the church have been sharply eroded over the last 50 years in the UK. In its place is a consumer culture centred on the fulfilment of individual desires and where the individual has become the core unit of social consumption. (Shaw and Woodward 2004, pp128-129)

Increasing medicalisation of distress is perceived to have roots in much wider societal changes than those relating more closely to the practice of medicine described above, and it is important to acknowledge these wider analyses. It is, however, beyond the scope of this review to provide a comprehensive breakdown of such broader societal changes here.

Conrad suggests that 'overmedicalisation' is the focus of much work, and it is important to state that medicalisation should not inherently be viewed *negatively*; indeed, Busfield (2011) suggests that in relation to mental illness and medicalisation, the boundaries of what is defined as 'mental illness' should be retrenched but the concept of mental illness itself (and its application to specific disorders) be retained with a much narrower definition. It is therefore not necessarily desirable to end medicalisation of distress, but rather 'overmedicalisation' that is at issue (Busfield 2011). It is also worthwhile pointing out that whilst medicalisation is frequently viewed in negative terms, Conrad provides a poignant reminder that medicalisation of distress is frequently borne out of good intentions:

Although physicians are no longer the major promoters of medicalization, there is an area in which physicians often still push the boundaries of medicalization. One of the major goals of the medical profession, and of

many physicians in practice, is to reduce the suffering of individuals.
(Conrad 2007, p.156)

It is important here to provide a brief statement about ‘medicalisation’ in relation to the analysis within this thesis. The study addresses (in different ways) how individuals come to seek treatment from a GP for their distress, which inherently means the application of a medical perspective to their difficulties. What this thesis *cannot* do is comment upon whether the application of a medical perspective is appropriate, or any other judgement about the suitability of medicine in these individual cases. This is for a number of reasons: I, the author, have no formal medical training, nor training within the fields of psychology, psychiatry, psychoanalysis or any other field that may confer the status of being able to ‘define’ a person’s problems within professional terms; I am unable to say whether they have received the ‘best’ response to their needs, from the perspective of any profession. My perspective is that of a medical sociologist; what I *am* able to do, is to study the process by which their problems have come to be *defined* and *responded to* by the medical profession. Critiques (and supportive arguments) of medicalisation reflect an acknowledgment of different theoretical perspectives, however their applicability to the individual’s stories within this study is beyond the remit of this work.

Having asserted that it is beyond the remit of this study to consider whether a medical response is appropriate for the study’s participants, I will now outline my position on the reality, or otherwise, of the concept of mental illness, as this has been briefly alluded to above.

Ontology and epistemology

It is important to outline whether this study views the existence of ‘mental illness’ as a definable, ‘real’ category. This is situated as part of a broader discussion about ontology and epistemology, as the reality (or otherwise) of the concept is inherently linked to broader philosophical discussions around knowledge and ‘science’, and in relation to the human body. I have endeavoured, through summarising a brief ‘history’ of the concept of mental illness (as well as in other parts of the literature review), to demonstrate

a reasonable foundation upon which to build this study: that current understanding around mental health (whether lay or professional) has its roots in history; that the boundaries of the concept are subject to change; that there are competing explanations that provide differing views upon causation and treatment; that what comes to be viewed as ‘mental illness’ may reflect broader societal concerns such as around social control; the category of ‘mental illness’ may reflect the values of those who come to define it (to name but a few points addressing the ‘socially constructed’ nature of the concept). Delanty and Strydom (2003) discuss recent trends within the philosophy of social science, and point out that there are some arguments (relating to a critique of positivism) that have come to be ‘accepted’, including by many positivists, that echo some of the points above:

- That ‘knowledge is historically embedded’ (Delanty and Strydom 2003, p.366)
- That ‘knowledge is socially contextualised’ (p.367)

They argue that whereas previous debates within philosophy of the social sciences centred around explanation versus understanding, there is a ‘growing debate between constructivism and realism’ (p.365). I will now provide a brief discussion of how this study views the ‘reality’ of mental illness, with reference to specific approaches to these two perspectives (that is, weak constructionism and critical realism), and how current debates are pointing towards the potentially ‘thin line’ (p.377) that divides them.

This study approached the topic from what Bryman (2004) would term a ‘constructionist’ ontological position; this is in opposition to ‘objectivism’. Bryman defines a constructionist position as follows:

Constructionism is an ontological position (often also referred to as constructivism) that asserts that social phenomena and their meanings are continually being accomplished by social actors. It implies that social phenomena and categories are not only produced through social interaction but that they are in a constant state of revision. (Bryman 2004, p.17)

This position calls for an approach to social science that is different to that of the natural sciences, and places an emphasis on ‘subjective meaning’, as opposed to accessing an ‘objective reality’. In relation to a corresponding epistemological position, this study adopts an *interpretivist* perspective. There are variants of constructionism, and I will outline the use of ‘weak constructionism’ to provide the perspective adopted at the start of this study.

As mentioned above, it is becoming accepted, including amongst some positivists, that knowledge about (and approaches to) a concept (and this would be extended to include medical) is to some extent shaped by its specific historical context. Hacking (2003) describes a weak constructionist viewpoint, that is commensurate with such a perspective; that a phenomenon, no matter how real in its physical existence (and he uses the example of teenage pregnancy), is viewed in a certain way depending upon its time and place. Continuing with Hacking’s example, a teenager becoming pregnant is an event that *occurs*, however, the concept of teenager – and the way that teen pregnancy is responded to within wider society – is heavily mediated by when and where it is taking place. Hacking’s version of weak constructionism does not deny any ‘reality’ that is ‘out there’, but rather he points towards the socially constructed nature of what it *means* to be a teenager who becomes pregnant; the *implications* are socially constructed. Continuing with this theme, Rogers and Pilgrim (2005) point out that ‘Judgements about health and illness (physical as well as mental) are value laden and reflect specific norms in time and place.’ (Rogers and Pilgrim 2005, p.11). Thus, it is important to take account of *some level* of social construction when considering any ‘illness’. There now follows a deliberation about the most suitable epistemological framework to use that balances an appropriate level of ‘social construction’ versus ‘reality’. With regards to medical concepts, Dingwall (2001) argues for the need for sociologists to balance two important competing obligations:

to be more critical of the positivist version of disease that was, and still is, hegemonic among our medical colleagues, and to insist that constructionist accounts cannot disregard the materiality of the human body and the disturbances to which its biology is subjected. Medical sociology remains pressed from both sides. (Dingwall 2001, p.vii)

Dingwall points out the necessity for medical sociologists to bear in mind the realness of bodily changes (that is, the idea of malfunction or disturbance) at the same time as the socially constructed nature of illness categories and associated implications; Dingwall cautions against treating concepts such as health or illness as *entirely* constructed. The concept of mental illness has a long history of contestation from the anti-psychiatry movement onwards; whilst there remain proponents on both sides of the argument (that is, strong constructivists against positivists) Bhaskar's (1978) critical realism provides a potential bridge between the two that concedes the existence of 'reality' (that is, there is some underlying reality to the concept) but views it as socially mediated. This perspective has proved popular amongst medical sociologists (see, for example, Rogers and Pilgrim (2005) and Pilgrim and Bentall (1999)). Such a position is critical of the categories and definitions employed in mental health care (and indeed of the provision of care itself) but do not necessarily deny that for some people, their inner experience is one that differs greatly to that of others, in a way that is disabling, frightening and creates vulnerability – that is, there is some 'reality' to the concept of 'illness'. (For example, Pilgrim and Bentall (1999) provide a useful critique of the 'wooliness' of the concept of depression, and its application to describe human misery in differing forms; though they do not suggest the concept of 'mental illness' be entirely discarded). Pilgrim and Rogers (2005) define a critical realist position (although they also term it 'social realism') as one that accepts reality as something that exists, but views human action (and concepts) as socially mediated. They describe an interplay between structure and agency as one where individuals are born into pre-existing structures but go on to affect, and be affected by, such structures (Benton and Craib (2011) point to a similar interaction between structure and agency using this approach). Pilgrim and Rogers (2005) suggest that critical realism provides a bridge between a social constructionist perspective and a positivist one:

Because critical realism is a materialist, rather than idealist, basis for social science... it can accommodate material causation (*e.g.* temporal lobe epilepsy) alongside a critical analysis of the interests being served by the way mental health problems are described and conceptualized in a

society at a point in time (*e.g.* a critique of the interests being served by psychiatric knowledge). (Rogers and Pilgrim 2005, p.17)

Such a perspective provides a way of maintaining the balance that Dingwall (2001) calls for. Indeed, Pilgrim and Bentall (1999) highlight the benefits of using a critical realist approach:

critical realism is a more helpful approach to mental health problems, as it ensures a proper caution about historical and cultural relativism, without degenerating into the unending relativism and nihilism attending social constructionism. This position respects empirical findings about the reality of misery and its multiple determinants but does not collapse into the naive realism of medical naturalism. It accepts causal arguments but remains sensitive to the relationship between empirical methods and pre-empirical (*e.g.* professional) interests and social forces. (Pilgrim and Bentall 1999, p.271)

They therefore argue for caution in uncritically accepting medical diagnoses such as depression, but nonetheless point out the benefits of (and likely need for) some form of support or help for individuals (1999); indeed, they argue that by considering depression as a medical concept, the real causes of human misery become obscured and can therefore not be appropriately addressed. They also concede the role of different interest groups in sustaining specific definitions of disorder.

Sociologists can continue to play an important role in highlighting the various challenges to a positivist perspective, as Busfield (2000) points out:

Geneticists' reported claims notwithstanding, social processes are crucial to the understanding of mental health and disorder in a range of ways. First, social processes shape the very concepts of mental health and disorder, thereby setting the boundaries of what constitutes mental disorder and the categories that are used to distinguish one disorder from another. Second, social processes play an important part in the aetiology of mental disorders – any mental disorder is always a product of genetics

and environment. And third, social processes play a vital part in influencing mental health practice. (Busfield 2000, p.544, emphasis in original)

Such an approach acknowledges that the concept of disorder is appropriate *in some way*, in that some people's inner experience varies in a way that can be viewed as disabling, and that this can be caused by various factors including biological and social. But this does not imply that the term 'disorder' is necessarily appropriate for the myriad of different experiences that may attract such a label. It is useful to point out here, that the terminology of mental illness, mental ill health and mental disorder (and any other variants used throughout this thesis) are used in open acknowledgment of the potentially contested nature of the applicability of the concepts to different aspects of the human condition. It is precisely their applicability to different internal states, as used or understood by individuals, that is discussed within this thesis. At the start of this project, the ontological position was one of weak constructionism, as outlined by Hacking (2003) above, and the epistemological position was one of interpretivism; whilst there is arguably a 'thin line' (Delanty and Strydom 2003, p.377) between weak constructionism and critical realism, the adoption of critical realism would entail a shift in ontological perspective from one of 'constructionist' to one of 'realist', which would entail a shift in perspective relating to the understanding of reality, including the adoption of some elements of positivism. Critical realists 'acknowledge and accept that the categories they employ to understand reality are likely to be provisional' (Bryman 2004, p.12), providing some reassurance against acceptance of reality as 'known'. One reason why constructionism is avoided by many writers is that it is viewed as being too extreme in its denial of reality; weak constructionism provides a potential counterbalance to this charge. Delanty and Strydom (2003) argue that 'it is important not to see realism and constructivism – indeed also cognitivism – as incompatible' (p.376-377). In addition, Collins (2003 [1998]) argues that social constructionism is *sociological realism*, an epistemological position that is commensurate with a constructionist ontology. He argues:

The social constructivist theory of intellectual life, far from being anti-realist, gives us an abundance of realities. Social networks exist; so do their material bases, the churches and schools and the audiences and patrons who have fed and clothed them; so do the economic, political, and geopolitical processes which constituted the outer sphere of causality. These successive layers of context for the minds of philosophers display no sharp borders. There is no criterion for arbitrarily stopping, for declaring that ‘I concede that social reality exists; but the world of material nature does not.’ It is all of a piece, all on the continuum *in medias res*. (Collins 2003 [1998], p.459) [Collins describes *in medias res* as meaning ‘that our thinking is always preceded by other thinking, our own and other people’s’ (p.458)]

These different epistemic frameworks provide relatively similar balances in relation to a trade-off between socially framed concepts and acknowledgment of ‘reality’.

As a result of carrying out this study (based upon its findings), an epistemology must be chosen that contains the possibility for *some level of reality* to the *causes of*, and *effects of*, extreme distress, whether viewed as a mental health problem, or as misery. Indeed, I do not discount the potential for a concept of ‘mental illness’ to exist, albeit with reference to calls to remove normal human experiences of misery from the concept (Pilgrim and Bentall 1999, Busfield 2011). Both weak constructionism and critical realism allow for this. Whilst the study findings will be more thoroughly discussed in later chapters, this dilemma was brought about by a new understanding of how the help-seeking process can be, in some cases, hindered by the experience of distress itself. Whilst both the perspective of weak constructionism and of critical realism allow for this, I have acknowledged the need to locate this study within a body of work that concedes some reality to the consequences of extreme distress, and of the potential for social causation as one possible explanation. However, this is not to deny the socially constructed nature of the concept, and as will be discussed in the proceeding chapters, the findings of the study also significantly point to shifting definitions of disorder, and the way in which the ‘medical gaze’ brings more and more people’s experience under the

label of 'disorder'. The resultant epistemological position therefore retains a strong emphasis on the extent to which experience of distress (and of its categorisation and seeking of help) is socially determined; the perspective of weak constructionism has been retained, although the potential utility of critical realism is acknowledged, as is the potentially fine line between the two (Delanty and Strydom 2003).

Having defined this study's ontological position with regards to the reality (or otherwise) of the concept of mental illness, and the importance of studying how individuals in the present day might construe their own distress and seek help, the next chapter will outline the study research questions, and how they have been operationalised.

Chapter 3

Methodology and method

This chapter will provide an overview of the study methodology and method. I will begin by defining the research questions, and then link these to the overarching study design, outlining how the use of qualitative methods most suitably addresses the research questions; I will also provide an outline of the analytic tools used. Following this, a detailed account of the research implementation will take place, providing detail as to how participants were recruited, so that any implications that this practical phase had on the research findings (*i.e.* how the study design shapes the findings) are more easily identified. I will then provide an overview of ethical issues that were included in, and arose from, the study design.

Research questions

Within the previous chapter I provided the background to this study; this involved setting the scene for a study that views mental ill health as a historically-specific concept whose remit (and associated care) has evolved over time. I provided an overview of the literature pertaining to the seeking of help, and outlined ‘the help-seeking problem’; the perceived role of lay understanding is also outlined. Within the section related to medicalisation, I discussed arguments pertaining to how an individual’s context frames how they view and respond to distress; in particular, that a person’s context shapes an individual’s desire for (and receipt of) a medical response to mental distress. This assumption is one aspect that is under investigation – to consider whether (and how) help-seeking is *framed* by its wider social context. This approach carries an implicit assumption that the behaviour of individuals in seeking help reflects the fact that help is available, as De Swaan’s (1990) argument suggests. One way of attempting to understand this notion of framing was by elucidating lay understanding in the area of mental health, and whether this played a role in help-seeking. This study sought to understand more about lay knowledge so that the impact of lay understanding is explored in relation to its content (and whether there are assumptions around the suitability and potential of mental

health care in providing relief from distress), and also in potentially illuminating lay referral networks that were discussed by Freidson (1970). Alongside this, the stories of help-seekers were sought, in order to find out what light they could shed on the help-seeking process over and above the relationship between help-seeking and lay understanding. The study sought to address these ideas through the following research questions:

The overarching research questions are:

According to the accounts of individuals, when and why do some people seek help from their GP when experiencing distress? What role does lay understanding play in this?

This question draws from the above discussion of framing, and seeks to explore what expectations people have/had of care, and how this might feed into actual help-seeking. In addition, there is an intention to consider what factors might affect why *some* people seek help when *others* do not, as this is a significant issue in help-seeking research. This overarching research question is addressed by the following sub-questions:

Research sub-question 1:

How do lay participants conceptualise ‘mental health’, ‘mental illness’, and ‘distress’?

- What do people think the terms ‘mental health’ and ‘mental illness’ apply to?
- When might individuals label psychological or emotional distress in terms of ‘mental health problems’?
- Do individuals perceive a difference between psychological/emotional distress, and mental health problems?
- What factors affect this categorisation or identification? What might help, or hinder, such classification?
- What is the nature of mental health problems, according to participants? *i.e.* what might cause, or help, them?

- When might participants consider seeking care from a GP as opposed to other forms of help that could be provided to someone in distress? (*i.e.* when is *formal* help recommended / sought?)
- What expectations are there of GP services in relation to this?

Research sub-question 2:

What reasons do recent help-seekers give for seeking help when they did?

- In stories of help-seeking, what pathways have participants travelled towards care?
- How did help seekers understand their distress, prior to seeking care?
- What other types of help (if any) were sought, prior to consulting a GP?
- What expectations do/did help-seekers have of care? What role did expectations play in their decision to seek care?
- What expectations do/did people have of their GP? Are expectations well-aligned with the care that is available through a GP?
- What accounts do individuals give for seeking help at the time that they did? What factors enable, or hinder, help-seeking?
- Are current theories around help-seeking adequate to explain current patterns and processes? What can be learned by a study of recent help-seekers' stories?

Research sub-question 3:

What is the nature of the relationship between lay understanding and help-seeking?

- To what extent does lay understanding play a part help-seeking? How can this study advance theoretical understanding about the relationship between lay knowledge and help-seeking?
- What understanding around mental health did help-seekers have prior to seeking help?
- Are help-seekers guided by a certain understanding of their distress? And if so, how did they come to define their distress in such a way?

- Is it possible to perceive a ‘framing’ of individuals’ expectations, by current treatment of mental ill health? Is this driving the medicalisation of distress?

These questions combine to provide an answer to the overarching research question from a very specific perspective *i.e.* one that seeks to explore whether help-seeking is driven by specific expectations of care, purposive action on the part of individuals in relation to how they interpret their own distress and also their own lay understanding. The different questions are not always neatly divided, and data from both groups contribute to the different research questions, to different degrees. Whilst each question is not necessarily neatly answered by one section of the data chapters, the chapters combine to provide insight in each of the question areas.

The questions draw upon the notion of framing that was outlined in the literature review; by understanding current treatment responses as contextually specific, some of the research sub-themes explore the interplay between current treatment responses and the beliefs that are held around these. In addition, the questions seek to provide insight with potential relevance to service provision in the following ways:

- how well-matched are beliefs around care (and help available from a GP) with the care that is currently provided?
- what barriers, or enabling factors, affect help-seeking, and might shed light on the current complexity in patterns of attendance in primary care?

The study therefore addresses help-seeking on a conceptual level (*i.e.* considers the suitability of help-seeking models in understanding current patterns), but also seeks to explore expectations of care, and the process of applying the label of ‘mental health’ to an individual’s experience, in order to understand more about how services are perceived and when they are viewed as appropriate by individuals.

Methodology and method

As mentioned in the literature review, a study that sought to investigate lay understanding and help-seeking was particularly relevant given the high profile of mental health in current health policy. There is also an attempt within the literature to reconcile two conflicting pressures: what underlies increasing demand for mental health services, and how to address the clinical iceberg (Pill *et al.* 2001) that is said to exist. An investigation into the role of lay understanding, alongside greater insight into help-seeking as a process, was intended to shed light on factors that might *increase* demand, and also on potential differences between help-seekers and non-help-seekers (with the underlying assumption that lay understanding, or other factors, may be responsible for keeping some people *out* of medical care). For this reason, the study sought to combine data from both the lay public (those who have not sought help via their GP) and recent help-seekers, to consider how lay understanding and the stories of recent help-seekers respectively might combine to shed light on the above. As mentioned in chapter 2, the study's epistemological position is interpretivist. Green and Thorogood (2009) point out the benefits of an interpretivist approach to health research; understanding patients' use of services, and the meaning that they make of symptoms in relation to their broader lives, can provide useful insight into how patients interact with (and comply with) care and suggested treatments. The study's aims are therefore congruent with such an approach; I will now outline the suitability of qualitative methodology and provide a detailed account of the study design.

The use of qualitative interviews

When considering the most appropriate method for such a study, the following assertion from Silverman (2000) is appropriate:

Of course, no research method is intrinsically better than any other; everything will depend upon one's research objectives. (Silverman 2000, p.93)

The study sought to access lay understanding around the nature of mental health using the words and concepts of participants as much as possible. In addition, the study sought to access the stories of help-seekers: their motivations for and expectations around seeking help, what other resources had already been tried, and how they interpreted their distress along their journey. For this reason, qualitative interviews were selected for both groups; qualitative interviews provide the following benefits:

- opportunity to explore each participant's views in-depth
- flexibility to probe responses and follow unexpected strands of discussion
- sufficient structure to address similar themes and/or areas of questioning amongst respondents within each group

It was important to select a method that would allow the opportunity to access the nuances of participants' responses, including the provision of illustrations, and access to the *unexpected*; specifically, I did not wish to rule out the possibility of participants discussing issues that had not been thought pertinent when designing the schedule, or indeed had not been thought of at all. Whilst the project had an *a priori* question to consider, it was also exploratory in nature and the potential for the *unexpected* had to be built in to the research design.

Recent work by Pescosolido (2011) advocates the use of mixed methods in help-seeking research, acknowledging that in order to understand the range of factors that feed into a person's help-seeking, the methods used must provide access to analysis that takes place on a number of levels (from an individual's perceptions, to their macro and organisational context). Recent research by Biddle *et al.* (2007) provided very useful insight into the utility of qualitative methods in the study of help-seeking. Central to *this* study, as with that of Biddle *et al.*'s, was the *meaning* that people make of their internal experiences, and the decision processes that they went through in coming to a decision to seek help. Qualitative methods are appropriate when attempting to access stories, in particular ones that are told using a person's own frame of understanding. Due to the emphasis placed on individuals' stories as the central

area of analysis, qualitative methods were deemed most appropriate to this element of the research. Quantitative methods have been usefully applied to the study of lay understanding (such as comparing attitudes between different groups within populations) as discussed in the literature review; the use of qualitative methods has been less common, with the work of Pill *et al.* (2001) the most notable qualitative work in the UK relating to lay understanding in the area of mental health, with more recent work of Sisley *et al.* (2011) and Brown *et al.* (2011) contributing to this area. Whilst the existing body of knowledge provides some insight into lay understanding, it falls short of being able to describe understanding in any length, what form it may take and if and how it is operationalised; therefore the potential for *exploration* is needed. Furthermore, the bulk of research into lay understanding takes place outside of the UK, with a focus on China (through the work of Furnham), Germany (through the work of Angermeyer and Matschinger) and Australia (through the work of Jorm) and so may be limited in its applicability to a UK healthcare context. There is little qualitative research into lay understanding and help-seeking (and in particular within the UK), and whilst a paucity of research using a specific method is not necessarily a suitable justification for selection of methods alone, this is nonetheless a useful outcome of its selection.

Focus groups were considered however these were not chosen as the aim was to garner individuals' in-depth understanding, in order to then consider what type of conclusions could be drawn from a variety of different, in-depth views. Focus groups do not provide the environment to pursue each individual's understandings in particular depth, but rather to allow a group discussion to emerge; one criticism of this method is that following this more collaborative approach, individual deviation (from the group's emergent discussion) might not be voiced. A semi-structured interview was selected to allow for the following of a loose thematic structure, with the potential for probing and emergence of themes that had not been previously expected by the interviewer. The label of semi-structured is loosely applied, and a different label of depth interviewing (Booth and Booth 1994) or focused interview (May 2001) could also be applied to the interviews with help-seekers in particular, because a part of those interviews involved following biographies of those participants; what is important to note is that each interview was intended

to have a topic guide so that specific *themes* were discussed in each, but with the flexibility to access views in depth, and pursue additional strands of interest if they emerge. My interviewing technique was influenced by Holstein and Gubrium's (1995) description of the active interview. They view interview data as co-constructed and that an interviewer should see their role as facilitating in this construction, and actively seeking out nuances of participants' beliefs; Holstein and Gubrium provide the following description:

Our active conception of the interview ... invests the subject with a substantial repertoire of interpretive methods and stock of experiential materials. The active interview eschews the image of the vessel waiting to be tapped in favor of the notion that the subject's interpretive capabilities must be activated, stimulated and cultivated...[interviewers] converse with respondents in such a way that alternate considerations are brought into play. They may suggest orientations to, and linkages between, diverse aspects of respondents' experience, adumbrating – even inviting – interpretations that make use of particular resources, connections and outlook. Interviewers may explore incompletely articulated aspects of experience, encouraging respondents to develop topics in ways relevant to their own experience. The objective is not to dictate interpretation but to provide an environment conducive to the production of the range and complexity of meanings that address relevant issues, and not be confined by predetermined agendas. (Holstein and Gubrium 1995, p.17)

Use of this approach in interviews proved successful in accessing additional depth from participants; I chose to probe by asking follow-up questions, seeking to find out the boundaries of opinions (*i.e.* when do they *not* apply; what are the caveats of these opinions) and inviting the participant to provide background and reasoning to their opinions as well as examples of their application. Seeking out the boundaries of opinions helped to uncover and explore any contradictions, as well as trying to understand more about the background of where their opinions might come from, but was not without consequence. For some, when discussing *hypothetical* scenarios, exploration in

depth was not always appropriate as participants expressed the intangibility of predicting potential reasoning; for some, this was not a problem, but for others it was not necessarily fruitful to follow (in-depth) paths of thought based upon hypothetical scenarios. In addition, there is the potential danger of *leading* participants towards an answer by significantly shaping the line of questioning. I attempted to avoid this by repeating what participants had said, as opposed to offering new paths of discussion, and this would often yield continuing discussion. At the point of analysis, concern around the possibility of leading questions was borne in mind when considering emergent themes, and careful attention was paid to the emergence of themes by examining scripts for any questions that may have led a participant to that response. Use of this active technique resulted in participants recalling specific experiences that provided illustration of their opinions, some indication of why they might hold the views they do (that is, some indication of its origin), and also how they felt about those particular experiences (and the people involved). Some participants did voice opinions that were derogatory to others in certain ways; this was somewhat surprising given frequently-voiced concerns that participants are likely to say things they believe the interviewer wants to hear (Radley and Billig 1996), and may suggest that participants felt comfortable expressing 'private accounts' (Radley and Billig 1996).

There are of course limitations arising from the use of semi-structured interviews, and these must be considered. Firstly, there is little or no opportunity to test opinions over time, with participant validation being a limited opportunity to test this; indeed, Blaxter (2010) has pointed out that understanding around health changes over time and so what participants expressed in their interviews represents their understanding at a particular point in time. There was little opportunity to build relationships over time, although all interviews represented the outcome of multiple contacts between interviewer and participant; however some participants (notably within the group of help-seekers who were relaying their help-seeking experiences) expressed that there was little point in taking part if they weren't actually going to be honest and open. Radley and Billig (1996) point out that stories about health and illness can be viewed as accounts and should therefore be viewed as not just the telling of events as they happened, but as also serving a wider

purpose of providing the teller with some form of ‘social fitness’ (Radley and Billig 1996, p.220). However it should not be assumed that the entire account serves the purpose of conveying social fitness. Whilst these accounts are constructed and serve purposes of telling, they also convey the sense-making that has taken place within the individual that provides coherence to their story; they convey participants’ perspectives on what has happened and why. They are likely to be a *combination* of both the ‘private’ and ‘public’ accounts (Radley and Billig 1996, p.232) that Radley and Billig describe based upon Cornwell’s (1984) distinction of public accounts that the speaker believes will be *acceptable* to the listener, and private accounts that the speaker gives to people they believe to be similar to them in some way – someone with whom they share terminology and assumptions. Williams and Calnan (1996) provide an alternative terminology of ‘orthodox’ and ‘unorthodox’ accounts, the main difference being the ‘presence of medical legitimation’ (Williams and Calnan 1996, p.52) in the orthodox accounts, and its absence in the unorthodox accounts (along with the presence of ‘self-legitimation’). Participants spoke openly about the shortfalls of GPs, and their own role in assessing the advice given *i.e.* that they may choose to follow advice or discount it, similar to the ‘unorthodox’ accounts of Williams and Calnan (1996). The accounts given in this study convey accounts of social fitness *and* of more private stories; of medical legitimation *and* disagreement with medicine and self-legitimation. These accounts are therefore viewed as containing complexity that is not easily reducible to ‘private’ or ‘public’, but rather conveys a complex mix that includes aspects of sense-making *and* seeking to be accepted. The expression of pejorative views (mentioned above) by some individuals indicates a level of private accounts as opposed to seeking to be accepted. Whilst it is important to bear in mind that participants may seek to be accepted in some way, it is also important to view the stories as they are told, that is, they are conveying the sense that these experiences make to the individual.

Research design

The fundamental aims of this research are: to examine lay understanding; to find out more about the relationship between lay understanding and help-seeking; and to use the stories of recent help-seekers to

shed light onto help-seeking more generally. In developing a research design, I considered the following crucial factors:

- speaking only to people who have sought help might elicit accounts that have been mediated by professionals; there was therefore a need to include lay public who had never sought help, to increase the ‘laity’ of accounts (the section on ‘laity’ in the literature review provides the rationale for this)
- speaking only to help-seekers would exclude people who have never sought help from a GP (but may have needed it); by including lay public, there is the *possibility* that some non-help-seekers might be included
- including people who have recently sought help is the most likely way to access stories of help-seeking, and to understand some of why it took place, when it did, in the way that it did
- if two distinct groups were recruited, it may be possible to make comparisons between them, in different ways: their lay beliefs, their attitudes towards help-seeking, and whether there were differences *other than* the experience of distress

The recruitment of two specific groups allowed for exploration of themes within each group (for example, the causes of mental ill health to lay participants), across the groups (for example, what type of help individuals *would like* in the event of distress) and comparison between the two groups (for example, hypothetical help-seeking compared to actual). There were some necessary differences between the two interview schedules to allow for discussion of help-seekers’ stories, however there were also areas of similarity to allow some comparison between the two groups.

In order to identify help-seekers, the action of seeking help for some form of distress, via a GP, would be the trigger; specifically, GPs were asked to pass recruitment information to people seeking help for the first time (the rationale behind this being that repeated help-seeking is likely to be framed by the experience of historical help-seeking, as was proven correct when some longer-term help-seekers were recruited). Not all help-seekers were new to

seeking help, and three participants were recruited who had long histories of help-seeking; for two of these participants – recruited via their GP – this had not been made clear to me prior to interview, and their histories only became apparent once the interview process had begun. Their stories were nonetheless useful in accessing different aspects of the help-seeking process and this is discussed more in chapter 5; their inclusion in the analysis was done so with their longer-term help-seeker status in mind. In order to select the lay public, the only specific requirement is that they did not identify themselves as having sought help for psychological or emotional distress from their GP. The nuances of these two categories were less clear-cut than anticipated, as I will discuss in the section on recruitment, below.

It should be noted that the study design was initially intended to include the views of GPs regarding meeting the needs of help-seekers. However, due to difficulty recruiting GPs, and practical consideration relating to the achievability of the study, this aspect of the study was not pursued; whilst it would potentially provide useful insight from a GP perspective, this aspect of the study was viewed as not wholly germane to the journey that help-seekers experienced *prior* to entering care. Rather, it was most relevant once help-seekers had reached care; thus, it was not central to the study's main aims. Two GPs were interviewed before this decision was taken. One of their interviews is referred to in chapter 6 confirming data regarding the expectations of patients, from the help-seekers' perspective. However, this aspect of the study is otherwise excluded from the write-up, as it was not pursued past its initial stages.

Before addressing the implementation of the study in any more depth, it is important to provide a definition of the terms used, so that the boundaries of the study are more clearly defined; I will now provide a brief outline of the specific definitions used in the study:

Psychological or emotional distress:

According to Busfield (2011), the term 'distress', whether described as 'psychological' or 'emotional' connotes: 'Subjective experience of sorrow and misery, without any necessary implication of pathology' (p.15). She also suggests that the use of 'emotional distress' is more closely aligned with lay

terminology, and that the term may also be broadened to include pain and pressure. The use of this term was intended to give a counterpoint to the more formal terminology of ‘mental health problem’, and to discuss when and how distress might come to be viewed within the paradigm of ‘mental health’, if it does so at all. As Busfield suggests, the term ‘distress’ is not itself synonymous with pathology, however it may come to be viewed as pathological either by individuals, GPs or both.

Help-seeking

The act of seeking help for the purposes of this study is rather tightly defined as attending a consultation with a GP (as this is the process under study). For reasons discussed in the literature review arising from the work of Pescosolido (1998), it must be conceded that this act may not necessarily be ‘rational’, that is to say, it may be haphazard, or the result of coercion as opposed to deliberate and purposeful help-seeking. Seeking help from a GP is likely to form part of a wider array of decisions and acts, and the study seeks to understand help-seeking from a GP within these broader processes; however, when classed as a ‘help-seeker’ within the study, a participant is someone who has been classed as having sought help from their GP specifically.

Common mental health problems

From a policy perspective, common mental health problems are defined as:

including depression, generalised anxiety disorder (GAD), panic disorder, phobias, social anxiety disorder, obsessive-compulsive disorder (OCD) and post-traumatic stress disorder (PTSD) ... Groups not covered include adults with subthreshold mixed anxiety and depression, adults with psychotic and related disorders (including schizophrenia and bipolar disorder), those for whom drug and alcohol misuse are the primary problem, those with eating disorders, and children and people younger than 18 years. (NICE 2011a, pp13-14)

Common mental health problems comprise a significant level of demand within primary care. I have already addressed the study’s ontological position

in relation to the ‘reality’ of mental illness, and take the approach advocated by Busfield (2011) – that there may be an underlying category of definable ‘illnesses’, however the boundaries of what is currently viewed as mental ill health should be retrenched; common mental health problems represent a potential terrain for such retrenchment. In addition, the study’s focus on ‘framing’ is more appropriately aligned with what De Swaan (1990) discussed as being ‘troubles’ reinterpreted in a different way. Whilst this approach could be applied to a greater area than ‘common mental health problems’, the study sought to address problems that are considered less severe, for the following reasons:

- the prevalence of common mental health disorders
- the inherent potential for ‘reframing’; whilst debates around medicalisation can be applied to a greater range of disorders than those classed as ‘common mental health disorders’, the debate around medicalisation most closely focuses upon problems that are less ‘severe’ and therefore more open to alternative explanations. This is particularly well-aligned with Busfield’s (2011) description of distress given above
- whilst there are numerous inconsistencies within help-seeking patterns, the potential for *over*-help-seeking (that is, what Horwitz (1996) described as ‘low need’ yet ‘high prevalence’) is most closely related to problems that are less ‘severe’, and thus this is an area of complexity with the potential for useful insight

The study therefore focuses upon people whose experience falls within the remit of ‘common mental health disorders’, conceding that there are other areas of care that are potentially fruitful as alternative areas of study.

Analysis

Analysis of data was carried out using two different processes (or tools) drawn from the process of grounded theory; I applied thematic coding, and the process of analytic induction. They are not mutually exclusive but are related to some extent, and I will discuss them in more detail below, after a description of the rationale informing the use of these two tools.

The two tools selected, thematic coding and analytic induction, were chosen in order to arrive at a point where any theory is reflected in, and ultimately grounded in, the data. Grounded theory itself was not suitable as a label for the process chosen, as I started with an *a priori* theory (that help-seeking might be framed by the services in place to deal with mental health difficulties; that lay understanding played a role in this). I will now provide some distinction as to how I have drawn from, but not *applied*, grounded theory. Grounded theory is a term that can simultaneously be applied to both a type of *theory* and also a *process* (Charmaz 2006). As a type of *theory*, it applies to theory that has been generated inductively, is grounded in data and has been verified against the data in a process of iterative feedback from data to theory and back again, through adherence to grounded theory *process*. Grounded theory is also used to describe a *process* of theory generation that contains certain steps, leading to the generation of such theory as described above. Grounded theory, as a *process*, can be flexible and can be tailored towards the needs and skills of a researcher (Charmaz 2006, Strauss and Corbin 1998). Grounded theory process can be adapted as a research project unfolds and Strauss & Corbin (1998) usefully point to such flexibility:

We emphasise strongly that techniques and procedures, however necessary, are only a means to an end. They are not meant to be used rigidly in a step by step fashion. (Strauss and Corbin 1998, p.14).

The fundamental principles of grounded theory (particularly the process of analytic induction, which is described in more detail below) can therefore be adapted and tailored towards the needs of a specific research project, and can be used in part or in whole depending upon the decisions of the researcher in relation to the wider project. However Bryman (2004) points to the need to be clear about the use of grounded theory; whether it is being used in its entirety in one form or another (*i.e.* Glaserian Grounded Theory) or whether only specific tools of grounded theory are being employed, and so I will now elaborate on my use of it. I have employed the following *tools* of grounded theory process:

- Data collection and analysis took place simultaneously as the project progressed
- Data was transcribed and coded, on an ongoing basis, so that ideas/codes can be compared with subsequent interviews using the constant comparative method (Charmaz 2006, Silverman 2006)
- Codes were considered, compared and combined to find overarching themes, and/or more abstracted categories
- Negative case analysis (the inclusion of deviant cases (Green and Thorogood 2009)) was used

Whilst I used some of the tools of grounded theory in order to carry out the analysis, I did not follow grounded theory as a complete process, for the following two reasons:

- I had already conducted a literature review
- I approached the collection of data with specific research questions

For this reason, I do not claim to have used grounded theory, only tools that form a part of it. In relation to the part of research that was addressing an *a priori* theory – specifically, that relating to the relationship between lay understanding and help-seeking – analytic induction is a more appropriate description of the overall process of analysis. Such analysis fits in with the existence of specific research questions and a degree of theoretical framing. For the exploratory aspect of analysis, thematic coding, as described by Green and Thorogood (2009) was used.

Analytic induction is a process that differs from ‘grounded theory’ as a process, as analytic induction is used in cases where a researcher has some prior theory or assumption to ‘test’. It can be summarised using the following set of stages:

- A rough, hypothetical, explanation for a phenomenon is created
- Cases are studied with this hypothesis in mind, and assessed as to whether they fit with the hypothesis
- If the hypothesis does not fit, it is reformulated to include the case, or the phenomena is redefined to exclude the case that did not fit

- New cases are sought to test (or disprove) the new hypothesis
- This process continues until a hypothesis (or ‘theory’) reflects all the cases, and there are no negative cases

(Shaw 2000, p.22)

Analytic induction involves the same iterative ‘feedback’ between data and theory as described in grounded theory (indeed the logic of analytic induction was elaborated and operationalised in grounded theory (Murphy *et al.*, 1998)), but does not require the absence of a prior hypothesis. Essentially, the process describes the iterative feedback between data and theory.

Having described two tools that were used in the process of analysis, I approached my data in two different ways, to obtain my findings:

- The first involved testing my prior hypothesis linking lay beliefs and help-seeking – using the process of analytic induction
- The second involved coding and abstracting the data to consider additional themes that emerged (aside from the prior hypotheses) so that *unexpected* themes may also emerge, attending to the exploratory nature of the research

As with grounded theory, analytic induction can be modified to the needs of a researcher and I applied the ‘logic’ of analytic induction (Murphy *et al.* 1998) to this project, recognising that such logic is frequently employed in qualitative health research on account of its conceptual rigour in the generation of theory whose limits and generalisability are explored as part of its conception (Murphy *et al.*, 1998). I applied the following processes in order to inductively generate theory that is ‘grounded’ in data (Silverman, 2006): iterative feedback between data and emergent theory, constant comparison and negative case analysis. I had initially intended to use theoretical sampling, but due to low recruitment this was not a possibility. This is discussed in more detail below.

The use of tools of grounded theory alongside the process of analytic induction is an appropriate ‘method modification’ (Grbich, 2007), and Grbich (2007) supports the creative application of methods to specific research questions. Methods should be adapted to meet the needs and skills of

researchers (Strauss and Corbin 1998). Such methods, and the subsequent analysis that is ‘grounded’ in qualitative data, can provide useful evidence for health policy and related research (Dingwall *et al.* 1998).

‘Participant validation’ was carried out, whereby study participants were contacted after the analysis stage, to potentially take part in a second meeting. The second meeting involved relaying the study findings to participants and receiving comments upon whether they felt the findings reflected their own experience, and whether they had any additional comments. This created the opportunity to check the analysis against the opinions of respondents, and also to present any additional questions that had arisen from the analysis (one such question is discussed in chapter 6). I did not carry out participant validation with members of the lay group, as there had been no new emergent themes in the later interviews, and I had already had the opportunity to test emergent themes with the later participants; I therefore felt that participant validation was not necessary for the lay group. Participant validation was therefore only carried out with participants from the help-seeking group, for whom the heterogeneity of experiences had meant there were some difficulties in finding ‘unifying’ themes. Participant validation was therefore a useful opportunity to test the emergent themes. There was no disagreement with findings, and participants elaborated upon, and agreed with, the findings that related to them.

Implementation of research design

The implementation of the project (and the practical matters that arose) not only impacted upon the data that was subsequently collected (this will be discussed on an ongoing basis) but also led to interesting observations that fed into a more nuanced understanding of the research topic itself. The following section addresses the fine detail of the research design relating to recruitment, so that deviation from design can be considered alongside the original aims. It should be noted that the recruitment of lay public began earlier than the recruitment of patients, as I was able to start the sampling process and also prepare the mailshot whilst waiting for NHS ethical clearance. It should also be noted that all participants were paid £15 for taking part in an interview (to be

given to them at the start of the interview). This is discussed in more detail in the section on ethics below.

The recruitment process

'Blurred boundaries': the unclear boundary between help-seekers and the lay participants

Recruitment of participants took place in two different ways, depending upon the group that was being targeted for recruitment. A number of mailshots (leaflets advertising the study, see Appendix 1) were sent out in order to recruit members from the general public, for the lay group (this process is discussed in more detail below). However, it became clear upon interview that some participants had indeed sought help to some extent, so recruitment did not take place across clear-cut boundaries and two people recruited through mailshot were subsequently categorised as help-seekers. Further than simply needing to 'reclassify' two participants, however, it became clear that the boundaries between lay and help-seeker participants are rather blurred. Even though seeking help from a GP is the specific event that denotes whether someone falls into the help-seeking category (for the purposes of *this* study), the line is not as clear as it might initially appear; within the non help-seeking category I interviewed participants who:

- had been distressed and sought help for physical accompaniments such as insomnia, in full knowledge of their own distress (but had not sought help for distress itself)
- had accessed counselling services through channels that were not related to their GP; in this instance their labelling as 'lay' remained correct based upon the specific interpretation of help-seeking used, however there has nonetheless been conscious seeking of help related to distress, through a different avenue
- had been to see their GP at a time of distress, related to their distress, but did not categorise this as seeking help for psychological distress because their distress was related to bereavement.

This range of examples usefully demonstrates some of the complexity surrounding help-seeking; it also demonstrates that when categorising for the purposes of research, participants do not necessarily fit neatly into research categories (of course, there is an element of arbitrariness to any categorisation). This is therefore a useful illustration of the complexity of presentations facing primary care. In addition, the reasons participants articulated for not seeing themselves as having sought help, provides further insight into the nature, and implications, of help-seeking. There was also great diversity within the help-seeking category (this is discussed in more depth in chapter 6, where I discuss the differing reasons why participants might seek help and whether 'expectations' is a useful way in which to categorise help-seekers' motivations). However, not all participants had sought help for the first time, and this did not fit the original target profile. These interviews nonetheless went ahead (indeed, disclosure of their previous help-seeker status usually took place *during* the interview) and so this matter was considered after the fact of interview. Ultimately, their transcripts were included in the analysis as they provided great insight into the help-seeking process nonetheless, and this is discussed in the appropriate sections of analysis. Whilst there was interesting data that could not be relevant to this study (such as experienced help-seeking that may fit within a framework of 'consumerism') there was also pertinent insight into patterns of non-help seeking, and historical avoidance of seeking help that could be compared to the experience of recent help-seekers. So, whilst this deviated from the original research design, the deviation proved to be useful and of relevance.

Recruitment of 'lay' public; the process, and a discussion of 'laity'

1. Sampling

As mentioned above, recruitment was carried out via mailshot. A leaflet (see Appendix 1) was sent out to houses that were spread across the area of Nottingham City. The research question was not based around a specific target demography, or group of people identified other than non-help-seeking status. The intention was to recruit a larger number, and once interviews and analysis were underway, subsequently use theoretical sampling to follow themes as they might emerge. Initially, therefore, I had no prior intention to target participants

with specific demographic profiles, and instead chose a spread of potential respondents with different socio-demographic profiles. Having said there was no targeting, it was necessary to ensure that there must be at least some homes targeted in more deprived areas as epidemiological data indicates that mental health difficulties are more prevalent in areas of deprivation than in areas of affluence. Areas of affluence were not excluded, as the intention was to access a *range* of participants in order to explore the research questions amongst contrasting participants (at least initially). In order to include areas of deprivation, and indeed to identify a spread of areas based upon some measure of deprivation, I selected The Indices of Deprivation 2007 (ID 2007), a study that provides comparative local data within a region, and also against national data.

Nottingham City is divided into twenty electoral wards. ID2007 provides data that breaks down each of these electoral wards into Super Output Areas (SOAs), which are geographical areas that constitute around 800 households each and so are comparable in size for the purposes of ID2007. The index ranks each SOA (and there are 176 in Nottingham City, spread over the twenty wards) from highest (*i.e.* the most affluent SOA) to lowest (the most deprived SOA) *within Nottingham*. These rankings are also compared to national data as mentioned above, using combined rankings in seven different domains (that is, different measures of deprivation such as income, employment and barriers to housing (ID 2007)) to provide the Index of Multiple Deprivation 2007 (which is given within ID2007, referred to as IMD2007). Through this, local data can be placed within a national context, and in relation to an overall score of deprivation – one that takes into account deprivation in multiple ways, as opposed to sole criteria such as barriers to housing or crime. To place the city in its national context, the following data is provided by ID2007:

- In the IMD, the overall measure of deprivation, 56 of the 176 City Super Output Areas (SOAs) are amongst the 10% most deprived in the country. 106 are in the worst 20%.

- The lowest ranking SOA in the City is in Aspley, which ranks 36th nationally out of 32,482, and is the only City SOA ranking in the worst 200 SOAs in the country.
- No SOAs in the City rank in the 20% least deprived in the country (ID 2007, p.3)

In order to obtain a spread in deprivation across this ranked list, I selected every fifth SOA for inclusion (that is, every SOA whose ranking ended with either a five or a zero), with slight adjustment to ensure that each ward had at least one SOA targeted. In total, 37 SOAs were selected for recruitment. It is important to acknowledge that use of any index has implications for the data selected; whilst it would be prudent to interrogate the scoring system applied to these domains (indeed the domains used), and associated implications, the index was used solely for the purpose of selecting homes that vary in their level of deprivation, so that I could select a diverse range in terms of recruitment. I therefore did not engage in an in-depth interrogation of the nuances of this index, accepting that its reliability is open to challenge; however, for the purposes of selecting a spread of homes, it will suffice.

Having selected the SOAs, I chose three streets from each SOA, and located each street on a map, attempting where possible to choose roads that were in different parts of the SOA, and also of different length/type (such as a cul-de-sac and a large connecting 'main' road). Having selected three roads in each SOA I then sent an invitation to houses numbered 5 and 10 (two houses on each street). This amounted to 222 houses to be targeted in each full mailshot (37 SOAs, each with 3 streets, each street with 2 houses). When I came to repeat subsequent mailshots, I used the same roads selected, but chose houses numbered 1 and 15 instead. (This was done to avoid using large house numbers as many roads do not have large numbers of houses). Notably, this strategy does leave out blocks of flats, which is a potential weakness in the selection strategy, although the study does still specifically include the most deprived areas of Nottingham.

2. Responses to the mailshot

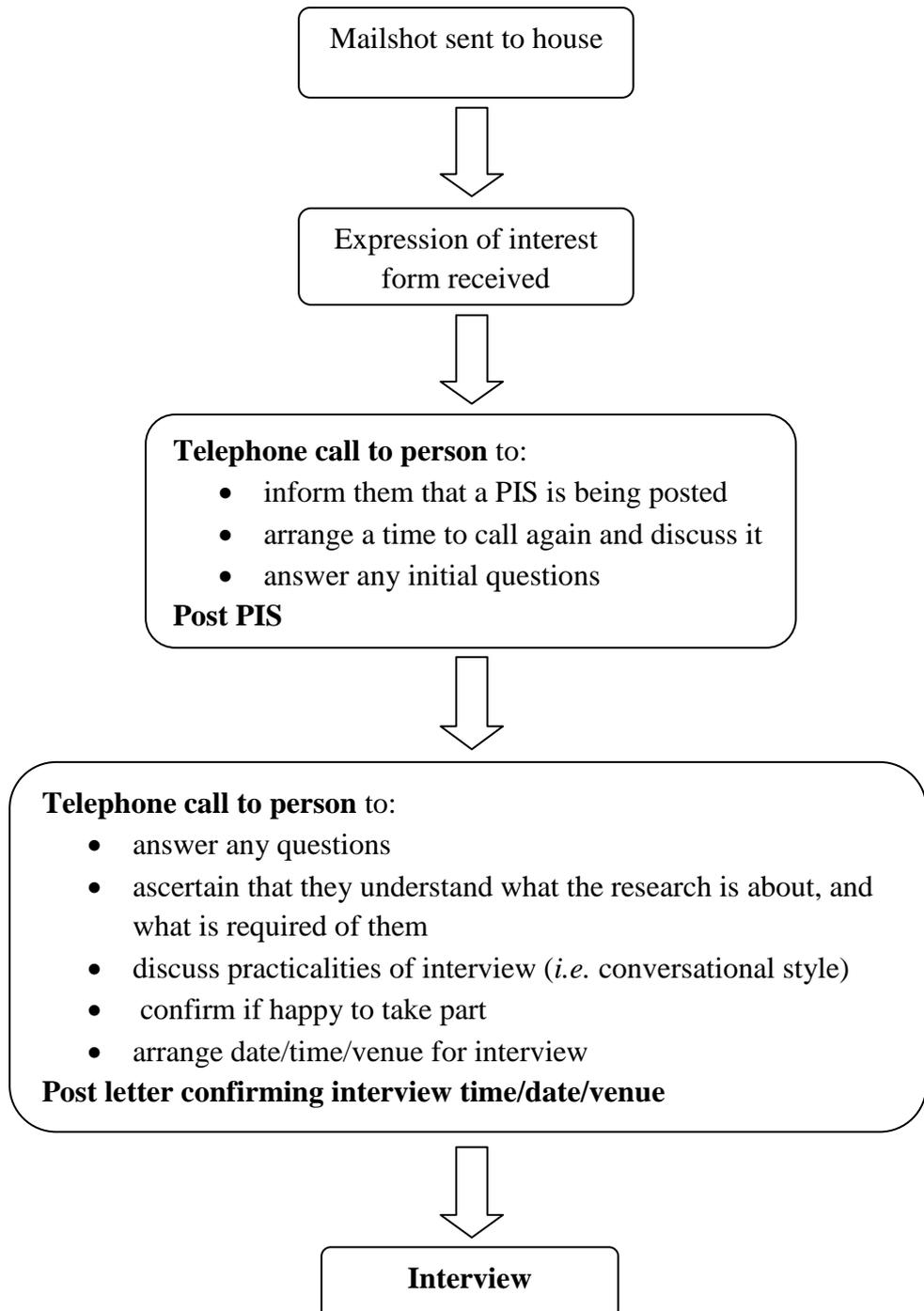
Mailshots were sent out in batches of roughly 100, with two rounds of mailshots encompassing the full 222 houses. Each envelope that was sent out contained a study leaflet (Appendix 1), and expression of interest (EOI) form (see Appendix 2) and a prepaid envelope. Initially, in the first mailshot, each envelope was addressed to 'The Occupier' and had a sticker in the top left hand corner stating 'Your invitation to take part in local university research', and was sent 2nd class. The first mailshot was sent on a week day, and there were no responses received. I reviewed my strategy, by chance, upon noticing my own habits with unsolicited mail, and decided to send out the second mailshot so that it arrived on a Saturday, given that I (and therefore possibly others) had more time to spend opening unsolicited – but possibly interesting – mail that would not usually be opened upon returning from work on a weekday. I also changed the sticker to read 'Your invitation to take part in University of Nottingham research', and possibly crucially, stamped each letter 'First Class Mail' just above this sticker. A second mailshot was sent out with these adjustments, and I received five responses. One of these was through snowball sampling. In total, seven mailshots were sent out, of around 100. One other mailshot received no responses; this may have been due to more people than usual being on holiday at the time of its sending, which was during the summer holiday period. Sixteen expressions of interest were received through this method (including the one person who was recruited via snowball sampling). Thirteen participants proceeded to interview; two respondents lost interest in the study and one respondent was deemed (by his GP) to be too emotionally fragile to take part; normally this person's GP would not have been contacted however he had recently (within one week of receipt of the recruitment materials) been diagnosed as depressed related to significant health problems and had not sought help himself. This person's potential recruitment is discussed more in the ethics section below.

Assuming approximately 766 envelopes were sent out in total, there was an overall response rate of 2% over all the mailshots, however if I remove the initial mailshot that arrived on a weekday, then this is increased to 2.5% (assuming 16 responses over approximately 650 envelopes). There was significant variety between mailshots, with the second notably generating five

responses (so, a rate in the region of 5.4%), which I attribute to being sent at differing times of the year, including summer holidays and bank holiday weekends.

3. Recruitment process following receipt of mailshot

The following flowchart shows the recruitment process that occurred when an interested party received, and responded to, the mailshot. The expression of interest form (EOI) and Participant Information Sheet (PIS) can be found in appendices 2 and 3 respectively.



The telephone calls served as an opportunity for me to answer participants' questions as part of ensuring informed consent, as well as an opportunity to familiarise myself with participants and start building a research relationship. Occasionally participants preferred text contact or letters, and this process was adapted as each research relationship unfolded (ensuring that at least one telephone call was held, for the opportunity to answer questions). The same can be said of the process described in recruiting help-seekers below.

Recruitment of help-seekers, and their gatekeepers

1. Recruitment of GPs

Recruitment took place through GPs as gatekeepers, as this was selected as the most suitable way through which to identify people who have recently sought help from their GP. Following gaining ethical clearance from Derbyshire Research Ethics Committee (REC) (to whom the study's ethical clearance was allocated), I approached several GPs by letter in order to recruit practices who might be willing to identify patients. This method did not prove successful and help was then enlisted from the local Primary Care Research Network (PCRN). Upon adoption of the study (following their formal adoption process which, for the sake of brevity, is not detailed here), the PCRN provided a significant amount of help. Help from the PCRN included:

- Help with recruitment, by approaching practices on my behalf through established research relationships
- Help with the costs to the practice that would be incurred through participation, by offering participating practices reimbursement of a £20 flat fee for participation plus £10 per patient recruited, to cover the costs of administration and other associated work.

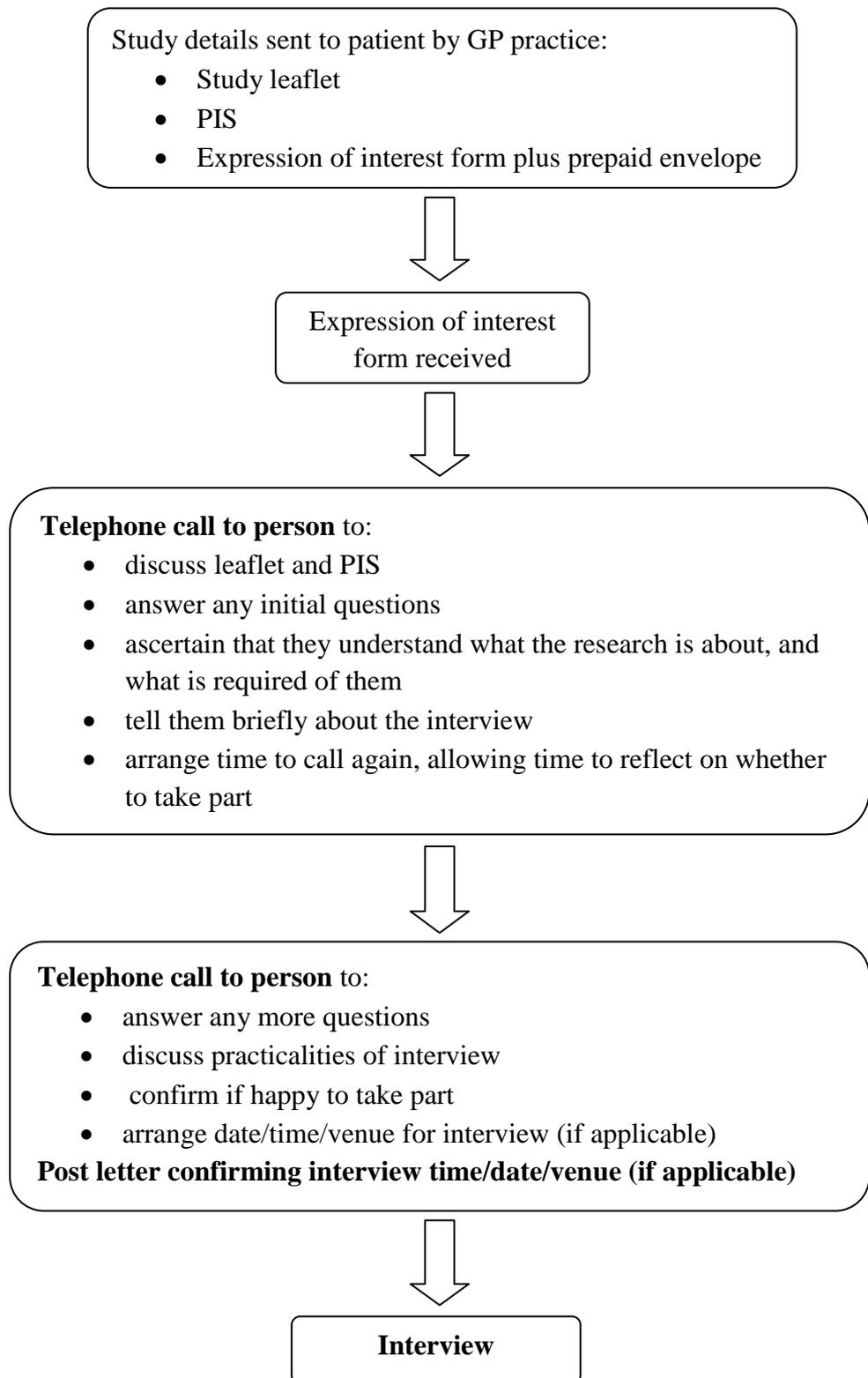
This support proved invaluable to the study and following the negotiation of participation via the PCRN contact, I recruited three practices through which to identify participants.

2. Recruitment process for help-seekers

The research design allowed for two different strategies used for recruiting help-seekers through GPs – (a) or (b), as below – and these were done according to the wishes of the GPs themselves:

- a) GPs to identify suitable patients during consultations and create a list of names as and when patients came to see them. These names would then be passed to the Practice Manager who would send recruitment materials on an ongoing basis
- b) GPs to compile a list retrospectively based upon consultations over the last month or other time period (this was left to GP preference however a maximum period of the last three months was set) and recruitment materials were then sent out in bulk, in one batch.

Recruitment materials were identical in both of these strategies – a cover letter from the Practice, a study leaflet, PIS and EOI plus prepaid envelope (see appendices 4, 6 and 5 respectively) – and served to pass study information on to patients without passing any patient data to the research team. Patients were then at liberty to respond directly to the research team themselves, using the EOI form. The following flowchart depicts the process for recruitment of interested parties:



Interviewing; the process, schedules and experience

1. Location of interviews

Whether or not a participant feels relaxed during an interview is likely to affect the depth to which they speak about a topic (Bryman 2004) and it is

therefore important, particularly in reference to semi-structured and depth interviews, that a participant feels relaxed in the interview setting. Whilst participant relaxation is to some extent beyond the control of any researcher, the choice of a location that is non-hostile, private, calm and quiet is likely to facilitate participant relaxation.

With this in mind, one ideal venue to carry out interviews was in participants homes. However, a venue must also be chosen with researcher safety in mind, especially as this research was being carried out by a lone female researcher. I drew from the Social Research Association's (SRA n.d.) *A Code of Practice for the Safety of Social Researchers* that usefully provides recommendations regarding choice of location as well as other safety considerations for a researcher, recommending that safety is a concern to be built into the research design. With this in mind, the research design initially set out that interviews would be held in two main venues, depending upon which group a participant was in. Lay participants' interviews would be held in a local third party venue such as a community centre near to the participant's home, so that it was reasonably convenient for the participant and also to ensure some level of interviewer safety (*i.e.* a public place where others might be present). Also, a community centre would not be associated with provision of NHS services and would be private (just the interviewer and participant in the actual interview room). A room on University campus was also available for this, where participants indicated that this was preferred to a local community centre. Lay participants' homes were deemed as a less safe venue than a public place, as there was no gatekeeping taking place in selecting participants (as there was with NHS patients). SRA guidelines caution against interviewing in homes of people where there has been little or no prior contact. With respect to NHS patients, the ideal preferred interview location was in the home, however there remained the other two options of a local (to the patient's home) community centre or a room on University campus. Patient's homes were deemed safer than those of the lay public, as patients were recruited through doctors and doctors were asked specifically to bear in mind that participants should be suitable for interview by a lone female researcher. In addition, patients would be aware that this gatekeeping had taken place and

that there was therefore some known connection between them and the researcher.

Specific procedures were created for the process of arranging and conducting interviews, in accordance with SRA guidelines on researcher safety in the field. For all interviews in the home, a safety procedure was put in place, involving a safety call by someone who had details of the location and time of the interview. A safety call was arranged to take place within fifteen minutes of the interview start time (to provide an excuse to leave if I felt unsafe, or the opportunity to request help in an emergency), and then again after two hours to check whether I had left the interview safely. In all home interview scenarios, I was able to engage in some prior contact over the phone with participants, and became confident in certain cases to omit the safety call that was scheduled for within fifteen minutes from the start of the interview (as this was felt to cause potential disruption to the interview); so, the procedure evolved to simply checking that I had left the venue safely. Ultimately, interviews were held over all three locations for both groups, depending upon the preferences of participants, and one participant from each group also nominated their workplace. Whilst using a variety of research settings may have implications for data gathered, the choice of location was made with participant preference in mind (with researcher safety as a second consideration).

Interview schedules

Lay participants

It is important to accept that when asking questions in an interview, different question types (and phrasing) might yield different responses in respect to lay understanding, as discussed by Popay *et al.* (2003). I will therefore outline the interview schedules in respect to lay understanding in particular (though I will address both interview schedules). It should be noted that the lay participant interviews did not involve the use of vignettes. Whilst vignettes are commonly used in research into lay understanding, and would provide useful insight into participant responses to specific disorders (as described in the vignette, for example ‘generalised anxiety disorder’), they would not necessarily give access to broader views around mental health, or about what participants did (or did not) classify as a mental health problem. I

chose instead to approach this issue in a number of different ways, in order to increase the extent to which I might tap into an individual's views, without necessarily defining the scope myself initially. Whilst it is important to define boundaries in some way, this was done later on in the interview when I had already asked participants to define their understanding in their own terms. The interview schedule is not included as an appendix as its thematic areas are summarised here. The following areas were addressed in the lay interviews:

- defining terms, such as 'mental health', 'mental illness', 'distress' and what might be encompassed by those terms
- asking participants what experience they had in relation to mental health, including formal training and experience in the workplace, and also personal experience in relation to mental health difficulty (self and others)
- asking participants to discuss appropriate help-seeking; what might constitute a 'warning' signal for seeking help, in themselves and also for other people (*e.g.* when might they suggest a friend seeks help from a GP)
- whether they had ever experienced extreme distress, or been concerned for their own well-being in this area (and what action had been taken)
- what they thought could help someone experiencing mental health difficulties (*i.e.* including non-medical and medical)
- what expectations participants had of GP help (and of treatment more broadly)

I focused on getting participants to define what they thought the term 'mental health' encompassed and then, once this had been established, I was able to focus upon certain definitions if necessary (*i.e.* focusing upon common mental health disorders where participants' understanding was of a much greater range). Boundaries were therefore more likely to be applied after some initial probing questions as to their broader understanding around the area.

Help-seeking participants

Interview schedules for help-seeking participants differed from the lay group in that the main focus was upon their story of seeking help, and this therefore reduced the proportion of interview time spent upon lay understanding. Essentially, participants were asked to talk about their story of seeking help (beginning in their own words); the following areas were then probed if not already covered:

- what led up to seeking help;
- how they'd interpreted their experiences prior to seeing their GP;
- whether they had tried any other ways of addressing their distress prior to seeing their GP;
- their expectations of GP care, and of their 'treatment', and whether their experience had met their expectations.

The last area of the interview was left for a broader discussion around mental health (*i.e.* definition, causation, amelioration), so that their 'lay' understanding could be ascertained following their experience (and in relation to their experience if relevant).

Both schedules were refined as the research progressed. Two pilot interviews were carried out for the lay schedule. No piloting was carried out for the help-seekers' interview schedule, as recruitment of help-seeking participants was proving more difficult; however, schedules were refined on an ongoing basis.

Transcription and analysis

I carried out transcription of all interviews. Qualitative software NVivo was used for the storing and management of data. Coding was not carried out using the software, as the process of open coding initially generated a proliferation of codes. Coding was therefore initially done using paper copies, and once a coding framework had emerged (that is, specific themes were apparent, as well as specific areas of participants' responses such as 'barriers to seeking help'), the software was then used to apply the coding framework to

the data. This helped to make retrieval of supporting data quicker, as well as providing the opportunity to revisit the data whilst applying codes, and check whether any apparent themes might have been missed.

Analysis involved interrogating the data in a number of ways. The first type of analysis was aimed at testing the hypothesis of linking beliefs to help-seeking, using the process of analytic induction described above, and this was done by:

- looking at lay transcripts only, including the use of open coding, to consider lay understanding and hypothetical help-seeking
- help-seekers' views were then included to see what differences existed, in relation to their lay understanding; whether expectations of care, or their lay understanding, played a role in help-seeking;
- the third element involved looking at help-seeking more generally and involved open coding of 'triggers' to seeking help;
- the fourth involved looking at help-seekers only, and considering **barriers** to help-seeking specifically;

After following these different steps, help-seeking was explained in the context of the different mediating factors affecting the help-seekers. This process helped to reveal that lay understanding played a limited role in help-seeking along with trigger events (as discussed in chapters 4 and 5), although the applicability of when lay understanding *did* play a role was also explored.

As mentioned in the analysis section earlier in this chapter, in addition to considering the relationship between lay understanding and help-seeking, thematic analysis took place. This was done in a number of ways, through experimentation, to see whether the data could provide useful insight into help-seeking in a way that had not been anticipated. This included:

- open coding of themes within stories, and then considering which themes applied across the stories
- examining responses to specific areas, such as the process of help-seeking, and what expectations participants had of GPs

Arising from this, an overarching theme of ‘interpretation’ and ‘networks’ arose (discussed in chapter 5), from the merging of themes at an abstracted level (what Dixon-Woods *et al.* (2005) termed a ‘second order construct’ (p.14) based upon Schutz’s original categorisation). Under these themes, different aspects of both groups’ stories were salient to the process (and outcomes) of seeking help. In addition, expectations and views around GP care could be viewed in relation to specific expectations (that is, the *content* of expectations), and in relation to considering whether purposive action is an appropriate way of understanding help-seeking (that is, the *role* that expectations played in determining action); both of these themes are discussed in chapter 6.

Data was analysed after every three interviews and themes were considered, then new interviews were carried out and analysis was revisited. It was not possible to test all emergent themes from the help-seeking group against new interviewees; this is because recruitment of further participants was proving difficult. In addition, due to the heterogeneity of help-seekers, some of the emergent themes could not apply to all, and these themes are discussed according to the limits of their applicability (this relates to data in chapters 5 and 6). With respect to the lay participants, theoretical saturation was reached and no new interviews were necessary; amongst the help-seekers, new interviews may have helped refine the themes, although I will discuss below (in the section on ethics) how the story of one potential participant – who did not take part due to the advice of their GP – provided useful confirmation of the themes discussed in chapter 5. Participant validation was therefore carried out amongst help-seekers only, as it had not been possible to compare all emergent themes against the stories of new help-seekers. Whilst the original intention was to use purposive sampling, this was not possible due to difficulties with recruitment of large numbers of help-seekers, and so the resultant sample is more in line with a strategy of maximum variation sampling. This has implications for the data, in that heterogeneity of help-seeking is *to be expected*. However, this also implies that help-seeking *is* heterogeneous, and that overarching themes are particularly relevant. There was a limited opportunity to test the findings from help-seekers, using the process of participant validation, which I will now discuss.

Participant validation

As mentioned above, I carried out participant validation with members of the help-seeking group only, as I had already had the opportunity to test emergent themes with the later recruits of the lay group. I sent an invitation to take part in a second meeting to participants who had expressed an interest in a second meeting. I sent invitations to the help-seekers who were specifically classed as 'new', as their stories were those most relevant to the study's emergent themes. Whilst the stories of the more longer-term help-seekers were also relevant to the themes, the emphasis of the study was upon new help-seekers; the number of invitations sent out had to be balanced against the feasibility of conducting meetings with everyone who responded. Six invitations were sent, and three people expressed a wish to take part. Two meetings proceeded, and one meeting did not take place, with the participant not being at their home at the allotted meeting time.

Ethical considerations

The study received ethical approval from the NHS Nottinghamshire County Research and Evaluation Department on 30th March 2010. For the sake of brevity, this section will provide a summary of the most pertinent aspects of the ethics procedure although the detail of the research design has already been discussed above (for example, the nuances of the recruitment process). In relation to ethics, I will address the following issues:

- ensuring informed consent
- issues relating to the involvement of vulnerable people in research
- the appropriateness of the research methods in relation to the involvement of vulnerable people
- issues relating to the payment of research participants

Ensuring informed consent

As mentioned above, recent help-seekers were recruited via their GP. GPs were given the task of identifying (and passing recruitment materials to) patients who had recently sought help for psychological distress, and who might be suitable to take part in an interview. GPs were required to identify

only people whom they viewed as able to give informed consent (*i.e.* having capacity), and this provided a level of gatekeeping for suitable participants. The process of arranging interviews (and of allowing potential participants time to read the recruitment materials and ask questions – see appendices 4-6) allowed for some interaction between interviewer and participant, usually in the form of two phone calls prior to interview; there was therefore some opportunity for me to build rapport with participants and establish that they understood the interview process, what the interview would be about, and what would be asked of them. This also provided the opportunity to assess for any level of confusion participants may have about the study, and indeed any other signs that participation might not be appropriate, such as expectations of therapeutic benefit. These two levels of gatekeeping, by GPs and then by the researcher, provided some level of confidence that participants were both able to give informed consent, and had also received sufficient and appropriate literature about the study as well as time to read it, and an opportunity to ask any questions (as already discussed above).

An additional risk with research amongst participants who are recruited through an NHS organisation, is that participants might perceive that future treatment could be affected upon refusal to take part. This was a concern addressed throughout the design process; indeed, templates for recruitment materials were based upon those advised by the National Research Ethics Service (NRES 2009) and one element of their suggested template design was in relation to this concern (see appendices 1-6 for all materials used in the recruitment of participants: appendices 1-3 for the lay group and appendices 4-6 for the help-seeking group). All literature sent to participants stressed that participation was on a voluntary basis and would not affect treatment. In addition, this was also repeated when telephoning participants, and every endeavour was made to point out the voluntary nature of participation, and also to be attentive to signs of hesitancy. Attention was also paid to when participants were difficult to contact, as this could be an indication of evading contact (which would be an indication of reluctance to take part); some effort was made to initiate contact with participants, however it was important to be sensitive to any perceived hesitancy or reluctance to take part, and where participants were repeatedly difficult to contact, this was viewed as indicative

of their wishes. Contact was then ceased, and a brief letter or text (depending upon the previously preferred format of contact) was sent thanking them for their help, confirming that no further contact would be attempted, and that there were no negative consequences of this. Only one participant declined to take part in an interview by ‘evading’ contact, and one participant declined to take part in a participant validation interview in the same way. Attempts were made at all times to respect participants’ right to withdraw their consent to take part; respect for participants’ preferred boundaries remained paramount.

The involvement of people who may be classed as ‘vulnerable’ in research – minimising harm

When considering the design of a project, it is important to consider whether the research design is appropriate for the respondents, and that no harm is done by involving people within the study (SRA 2003). This applies to people who are not considered vulnerable, but when vulnerability is present the issue of harm is even more pertinent. It is therefore important to consider whether and how the study might be appropriate for people with mental health difficulties to take part (this will be discussed more in the section below), how any risk of harm can be minimised, and what should be done in the event of any problems. I will therefore address these issues in turn.

The interview involves recollection of participant’s experiences of distress, and the recollection of these experiences could be potentially distressing to participants; alternatively, the process may also be cathartic. The recruitment material points out that participants will be asked to discuss their experiences of distress, and to make their decision about taking part with this in mind. A self-selection process should therefore already have taken place, with those who feel uncomfortable discussing their experiences, not taking part. Whilst this does not guarantee that no one will become distressed in the interview, participants are aware in advance of what will be discussed, and so have this in mind when deciding to take part. The interview process itself is semi-structured, and so there are specific topic areas to be discussed but also significant flexibility to probe and tailor questions to a participant’s own experiences; in addition, there was usually a significant amount of time allowed for interviews to take place (*i.e.* the hiring of a room in a community

centre for two hours), so interviews could move at whatever pace appeared most suited to the participant. This meant that the interview situation allowed for a conversational approach, with a sensitive and respectful questioning style that allowed respondents the opportunity to take their time over their responses; the interview setting itself was therefore as relaxing as possible. However, these factors alone do not guard against the experience of distress, and there were more structural processes in place to help guard against unnecessary distress amongst participants. Participants were assured that they:

- could terminate/leave the interview at any point, without negative consequences
- could choose to not answer a question that they did not want to; if they did not wish to express displeasure at a question, then saying 'I don't know' would move the questioning on
- should respond in as much depth as they felt comfortable with
- could request a break at any point

Despite these measures, in the event that a participant did become distressed, then the following procedure had been arranged, in collaboration with my academic supervisors:

- Terminate the interview, in terms of data gathering
- Provide appropriate comfort to the participant, such as a tissue, gentle encouragement
- Attempt to ascertain the reason for their distress, giving them the opportunity to talk about it if they wish
- Decide upon whom to tell about the participant's distress (having discussed their own preferences).
- Communicate the decision to the participant, and then follow up this decision by communicating with the selected person
- Agree on a follow-up telephone call with participant in one to two days if they wish (in order to check on whether distress remained or had passed)
- Reassure them that there are no negative repercussions of terminating the interview

- Remain with them until I felt assured that their distress had reached a manageable level

In addition, I had a telephone number of an emergency contact (such as one of my academic supervisors) so that should a situation arise in which I was uncertain what to do, I would be able to call and instantly receive advice. Fortunately there were no occasions upon which participants appeared to be distressed; indeed, most participants expressed that they had been happy to take part, and that the opportunity to express their opinions and experiences for the purposes of research had been positive.

The appropriateness of interviews, for people who have recently experienced (and may still be experiencing) distress

The ethical clearance procedure required clarification of the potential gains of carrying out the study versus the potential risks. It was necessary to consider whether the findings of the research could be useful for the future provision of care, and indeed this is one of the aims of the study. The design of the study included the involvement of recent help-seekers, as one of the aims of the study – to find out more about the help-seeking process from the perspective of people who have gone through it – could not be achieved without help from such a group. However, as discussed above, any potential harm must be minimised (indeed, avoided) and the methods used in the study (qualitative interviews) must be considered in terms of their suitability for people who have recently experienced (or continue to experience) psychological distress.

Having briefly discussed (above) the flexible nature of the interviews, and the potential to adapt to participants, it is important to consider the use of such interviews in more detail. As mentioned above when discussing the research design, the description of the type of interview used could vary between ‘semi-structured’, ‘depth’ (Booth and Booth 1994), ‘focused’ (May 2001) or ‘unstructured’ (Corbin and Morse 2003) depending upon the definition chosen; Booth and Booth (1994) point out that no interview is actually ‘unstructured’, as the interviewer has in mind the subject area to be discussed along with different themes within that subject area. Whilst there are

some minor differences between these types of interviews, they share the common ground of focusing on some aspect of participants' lives and asking participants to tell their own story, using their own words, sense of timeline and their own priorities; at the same time, the interviews each had certain topic areas that were to be addressed. The interview format had certain key areas to ask (should these not have already arisen) but the main focus of the interview was to elicit participants' stories in their own words, in order to understand their actions, feelings and expectations during their process of seeking help. With the emphasis on the participant's own story, Corbin and Morse (2003) point out that this gives participants a certain element of control over what is said; participants are in control of the story, what is revealed, emphasised and omitted. Corbin and Morse also point out that while there is the risk of distress being experienced, it is not necessarily greater than the risk that distress could occur during everyday life, and report frequent experience of participants experiencing participation in a positive way. Booth and Booth (1994) point out the importance of allowing plenty of time for interviews to take place, so that they can proceed in an unhurried manner that allows a conversational style to develop; such a factor is important in creating a relaxed environment that allows participants to proceed at their preferred pace. Ultimately, the style of interview selected was conducive to participants framing their experiences in their own words, without significant time pressure and in a setting chosen by themselves, creating an environment as enabling as possible (within the constraints of an interview setting). Whilst an interview did risk the potential for distress to occur, about which participants had been warned, my focus was upon participant safety above data collection and interviews followed the cues of participants; where participants seemed uncomfortable or wishing to move away from a subject, such cues were noted and followed. Ultimately, no one vocalised the experience of distress arising from the interview (nor were there any instances of distress being apparent) and participants frequently expressed positivity in having someone listen to them, and in their experience being perceived as of potential value in helping others (albeit the limitations of research findings as being of benefit to others were discussed).

Payment of research participants

Participants in both the lay and help-seeking groups were paid £15 for their participation in an interview. Payment of research participants is typically used as a way of enhancing recruitment for a study (Cleary *et al.* 2008, Dickert and Grady 1999); this raises the need to address the ethics of paying participants, and whether a payment is viewed as an ‘inducement’ that increases the possibility of harm by reducing the extent to which an individual might prioritise their own well-being (Cleary *et al.* 2008). There is also a risk that this will affect the power relationship between interviewer and participant (Dickert and Grady 1999). Some writers discuss the differential implications of paying participants who are healthy, but not paying participants who are ill, as Cleary *et al.* (2008) and Dickert and Grady (1999) point out; payment of people who are ill might additionally skew their perception of the benefits of taking part, in particular if their clinician is also the researcher (Dickert and Grady 1999), and people who are ill are inherently more vulnerable than those who are not. Financial payment may also lead to disproportionate recruitment of people from socially disadvantaged backgrounds. Cleary *et al.* (2008) stress that payments must not be disproportionate, in order to avoid unduly inducing people into taking part, and so the size of a payment is important.

The method of payment selected falls most closely in line with what Dickert and Grady (1999) refer to as the ‘wage-payment model’ (p.199); such a model uses a payment of a set amount (relating to the hourly cost of unskilled labour) that recognises the time and effort that people put in to attending an interview, and providing some compensation for that effort. The idea behind such a model is that it should not offer significant inducement, based on its parity with ‘unskilled labour’. This method differs from what they term the ‘Reimbursement model’ (p.200) that covers only the financial expenses incurred in attending an interview, such as travel and parking; such a method more greatly reduces the chance of inducement by removing any possible financial gain from participating, and only addressing the costs that a person directly incurs. One disadvantage of this method is that it potentially leads to participants actually incurring other costs, should they need to miss work to attend an interview, pay for childcare, or other such related factors. Dickert and Grady (1999) prefer the wage payment model, suggesting that it provides only

a low level of inducement (if at all) and recognises the time and effort that people put in to attending an interview, over and above the costs they incur in getting there. Whilst there are arguments that payment of research participants might encourage people to participate for reasons different to the ideal of altruism (Cleary *et al.* 2008), there is also an argument that payment of participants provides meaningful recognition of their effort and time (Russell *et al.* 2000). Payment does not necessarily affect informed consent if it is at a reasonable level (Grady 2001). Indeed, Grady argues that:

An amount of money that is not excessive and is calculated on the basis of time or contribution may, rather than constitute an undue inducement, be an indication of respect for the time and contribution that research subjects make. (Grady 2001, p.40)

The area remains one of debate, and in acknowledgement of potential difficulties in this area, I endeavoured to select a payment level that was low enough to avert undue inducement but sufficient enough to recognise and thank people for their time and effort. Based on the assumption that interviews might last between 60-90 minutes, I chose an amount of £15 (recognising that interviews may be briefer, or last up to two hours). A single amount was chosen in order to avoid calculations and differing payments from one person to another (what Dickert and Grady (1999) would term an ‘egalitarian’ payment); some participants were interviewed in their homes and incurred no costs, others travelled to a venue and did incur some cost. One interview lasted only half an hour, whereas two others lasted almost two hours. A flat fee of participation was set to avoid the need for calculations, and indeed so that participants could be paid before the start of the interview so that they were free to leave the interview when they chose. Thus, whilst the ‘wage-payment model’ is the closest model to that chosen, there was no actual calculation of time spent, viewing the payment as recognition for effort as opposed to payment that was timed and awarded incrementally; it could alternatively be viewed as a ‘one-off gift’ (DH 2006, p.18). Payments were made in cash, as recommended by the Department of Health (2006) in their guidelines for

payments to service users. Participants from the lay and help-seeking groups were given equal payments.

A note about service user involvement

Whilst the involvement of service users in the design of research can help research design to be more sensitive to the needs of services users (such as rewriting questions so that they are more easily understood) and more relevant to the experiences of service users (Faulkner 2005), no service users were consulted in the design of this study. This was for two main reasons: Szmuckler (2009) highlights the first reason – he discusses the tendency for researchers not to include service users due to fears around losing control of the research design, and a lack of training resources to enable services users to meaningfully contribute to the research design – both of these fears were present; the second reason was not knowing specifically how to access service users, given that the design of the study needed to be in place prior to applying for ethical clearance (an assumption at the time, being that ethical clearance might need to have been attained before accessing service users). Regrettably, as a PhD student near the start of my research career (at the point of study design), I was affected by the fears that Szmukler discusses: fears around control of the study and of service user training, plus a lack of information as to where to access service users who might be able to contribute to the study design, prior to the receipt of NHS ethical clearance. Indeed, as the PhD is a body of work that is largely conducted by a sole researcher, I was concerned to retain control of a study for which I would need to be able to defend and explain *every* decision, and to bear sole responsibility for its outcomes. Whilst these concerns can easily be overcome by accessing service users through established networks (such as the Mental Health Research Network (Szmukler 2009)) and allowing service user decisions to shape the design by embracing the benefits that involvement can bring, such perspective is not necessarily available to a researcher in the first few months of study, when crucial design decisions are taken. For this reason, research design was carried out based solely upon reviewing literature and upon consultation with supervisors.

An unanticipated ethical dilemma

As mentioned in the section above relating to recruitment via *mailshot*, one person responded to say that he would like to take part, and that he had recently been diagnosed as having clinical depression (the week prior to receiving the leaflet advertising the study). His story is pertinent to the study as well as to a discussion of ethics, and so I shall summarise it now. The person, a male who I shall call 'David', indicated that he had no idea that he had been depressed; he had cancer, had been undergoing chemotherapy and had just found out two weeks ago that his cancer was in remission. Prior to that, he'd been told that the success rate of his chemotherapy was 90%, although he felt that he would be in the 10% for whom it would not work. Whilst at a recent consultation relating to his treatment, a nurse identified him as depressed, and advised that he seek care from his GP. He indicated he'd had no idea that he was depressed, and that he was simply trying to come to terms with the possibility that he might die, the invasive treatments (and the effect that they had on his life) and the continued medication (steroids) that he was taking, as well as waiting to find out where or not his cancer would prove fatal. To find out that he was also depressed was a shock to him. He said that following finding out about his cancer's remission, a lot of his stress had gone. He also said that help on stress-related problems was non-existent, and that apart from his GP he would have no idea where to go; he specifically said that until someone (a nurse) told him where to go, or where to look, he had no idea help was available. He wanted to take part in the study because he thought he might be able to help, or it might possibly help him. He had been unable to talk to people about his experience, including his family, and 'the chance to talk to someone would be lovely'. This was relayed in a telephone call that was held upon receipt of a telephone message that David had left indicating his wish to take part in the study.

Because he had recently been diagnosed as depressed, and because most recruitment for people with current difficulties was taking place via their GP, I consulted with my supervisors to see if I should proceed with the interview. After relaying details about my discussion with David, my supervisors advised that his participation would be potentially suitable, but that it would be appropriate to obtain David's consent to contact his GP, so that his

GP would be aware of his participation and could act as a suitable person to contact in the event that David became distressed by his participation (in line with the procedure that had been established in the event of a person's distress, discussed above); David's safety was paramount and it was important that his well-being be safeguarded, especially in the event of increased distress. David was happy for me to contact his GP on his behalf, and he gave me their details; I then sent a letter to his GP outlining the study (including a study leaflet and REC approval details) and asking if they were happy for David to take part, and to be contacted in the event of David becoming distressed. A few days later I received a call from his GP, who was very surprised to hear about the study, and that David had been highlighted for it, as his depression had only been diagnosed very recently. I explained that David had received one of my leaflets through the post, as part of a mailshot that had been sent to selected addresses – that his selection was a *chance event*. His GP said that she did not feel participation was a good idea at that time, because he was very fragile, and very easily upset at present. Having received his GP's advice that she thought an interview was not appropriate, I felt it important to follow her advice and not proceed with an interview, as to do otherwise would be indefensible in the event of any problems. I then wrote to David thanking him for his interest in the study, but relayed that after consultation with his GP, it was felt that an interview might be upsetting at that time, and that I was keen to minimise the potential for additional distress to him.

I have included this story about David for two reasons; the first is that his story is highly relevant to two of the themes in the findings discussed in chapter 5 (that of distress being identified whilst present in a medical setting, and also the difficulties in interpreting anything as being 'wrong' when experiencing incredibly distressing circumstances). The second is because it represented a potential ethical dilemma; whilst it is essential to ensure the well-being of participants in the study, and to minimise their distress, this also meant that in this instance David's own wishes were not followed. David had expressed a wish to take part in the study, and to talk about his experience. This raises concerns around David having therapeutic expectations about taking part, although a counter to this is that he simply stated that he would like the opportunity to talk to someone about his experience, and this need not be

perceived as therapeutic in itself. However, my main quandary was that, whilst it was *essential* to safeguard David's well-being, because he had been recruited through an unconventional route and was currently distressed, his own choice about participation was partially removed from him. His diagnosis of clinical depression (and his currently distressed state) acted as a trigger for me to consult my supervisors, and for them to suggest I consult his GP. Whilst there are good reasons for this – specifically, a concern for his safety, a concern to minimise exposure to the risk of additional distress, and a safety net in the event that participation did increase his distress – his decision had nonetheless been taken away from him, because he had recently been diagnosed as depressed and was still experiencing some distress (*i.e.* he was still vulnerable). David was not the only help-seeker who was recruited via mailshot, although in the case of the other people (who were not currently distressed) there was no perceived need to contact their GP. Nor was David the only person currently distressed to be considered for interview; most of the help-seekers who were recruited via their GP were in a current state of distress. David's unique position was that his GP had not been a gatekeeper and yet he was currently distressed, and this meant I felt the need for caution when considering him for interview, so that there was some form of GP support in the event of increased distress. Whilst there will have been an element of gatekeeping occurring with all participants who were recruited via their GP (*i.e.* GPs made a decision about who was appropriate to take part, without me being aware of those who were not selected), this was the only occasion when the process took place in a different order, and showed the difficult balance of respecting the individual's wishes and also taking into account the views of professionals who are related to their care; on this occasion, I felt that the need for caution ultimately led to David's own choice being removed from him, even though each person consulted responded with David's interests at heart. Sayce (2000) points out that for some people labelled with a diagnosis relating to their mental health, their own decision-making can be called into question by others who are acting in their best interests; this can even happen at times when the individual is able to make decisions for themselves. I was concerned that this series of events, borne out of a sense of caution and of concern, might have culminated in such an instance. Even though it was important that I proceeded with caution, this

had to be balanced against the possibility of David's own decision-making being taken away from him. I do not disagree with any of the advice I received, because every person who was consulted acted in a way that placed David's safety as a central concern (including my own decision to consult my supervisors), and this was an appropriate response. However, as a result, David's own wishes were not followed. It may be that it was the most appropriate decision to exclude David from the study; no additional distress was caused apart from being told that he could not take part. However, Sayce's poignant argument that the process of labelling can lead to a person's ability to make their own decisions being removed from them, serves as a salient counter to the safety nets that, perhaps rightly, prevented David from participating. This serves as an illustration that appropriate and ethical behaviour can involve a 'grey area' where no one option (that is, to participate or to not participate) is entirely free of implications for the potential participant. Regrettably, the potential for such a dilemma had not been anticipated prior to the sending out of the mailshot.

It should be noted that in the following chapters (and in appendix 7), pseudonyms are used instead of participants' actual names. In addition, where stories are discussed, recognisable details have been slightly altered to help disguise participants' identities yet retain a sense of their story. In appendix 7, participants' ages have also been slightly altered to help protect anonymity.

Reflection upon the role of the researcher

It is important to reflect upon my own role in this research – my demographic profile, my own lay understanding and my experience as a help-seeker – in order to illuminate how my presence (as opposed to that of someone else) has shaped this study. This has been included early on in this thesis, as opposed to at the end, so that the reader is aware of my own status – in relation to that of my participants – throughout.

With regards to my demographic profile, I am a female, and was aged between 31 and 35 for the period of the research (from design to write-up). I was employed prior to starting this PhD, and am unmarried with no children. For the purposes of the study, I would be classed as a help-seeker, in that I

have attended a consultation with my GP in relation to experiencing distress, in 2001. My own help-seeking story was that, following the unexpected death of my mother, whilst I was living and working in Australia aged 24, I was struggling to cope with grief upon moving back to England following an early end to my travels. I had been an occasional carer for my mother, who experienced long-term mental health problems. I was raised by her in a single parent family with the assistance of my grandparents, who also passed away whilst I was travelling. I was finding the process of adjusting back to life in England (as well as coping with the loss of the people with whom I grew up) rather a shock, and for a few months after moving back to England I experienced panic attacks. During a routine attendance at a local clinic relating to contraception ('routine' being the requirement for having my blood pressure measured in order to receive a repeat prescription for the contraceptive pill), the consulting nurse asked me how I was doing generally, to which I replied that I was struggling to cope with grief and adjusting to life back in England. She said that she would mention this to my GP on my behalf, and within a day or two I received a phone call from my GP to arrange an appointment. I attended, and after talking about my experience and about not knowing how to deal with my grief, I was referred to a community mental health team for a short period of counselling (and the option for signposting to additional, private counselling once this ended).

Initially, upon reflecting on my own experience and whether it might be in any way useful to my carrying out this study, I assumed my experience might be useful in giving me a small measure of 'insider' status, as opposed to 'outsider' (Corbin Dwyer and Buckle 2009). Even though I did not consider myself as having received treatment for a 'mental health problem', I had experienced counselling and had some understanding of the stigma associated with that minor 'association' with mental health services (in relation to telling my employers, for example). Indeed, at the outset of the research, I did not consider myself as a help-seeker, as I did not consider my experience as relating specifically to a 'mental health problem'; I subsequently came to reinterpret my status as being a help-seeker, not because of the nature of my 'problem' (and whether it should be viewed within the category of mental health) but because I was experiencing extreme distress and attended a

consultation with a GP, the criteria for help-seekers in this study. My memories of receiving help related mostly to my feelings of fear and surprise upon being referred to the community mental health team. Specifically, I felt shocked at being referred to a team labelled 'community mental health' when all I felt was 'wrong' was the experience of (understandably) intense grief; I therefore assumed that the most pertinent aspect of my experience would be my experience of this shock, and some experience of receiving counselling. In chapter 7 of this thesis, I briefly reflect upon my own experience in relation to the study's findings; however, as these have not yet been discussed within this thesis, that aspect of reflection will be addressed later.

From the point of view of holding my own 'lay' views, it could be argued that my views have been professionalised for having received some form of counselling and the potential reframing of my own experiences that might accompany it; this is in addition to the shaping of my views through academic literature. It is useful therefore to reflect upon how my views and their development, so that my own position is explicit

At the point that I received help from a GP, I viewed mental health as a concept, or subject matter, that was both serious, 'real' and potentially debilitating for those who experienced mental ill health. This was in no doubt based upon my experiences of growing up with a parent who suffered from mental health difficulties that would sometimes lead to hospitalisation. I had also frequently been told by (well-meaning) others, that mental health problems were hereditary. I therefore viewed the concept as something that was 'real' and with a likely biological and/or genetic component. Although beliefs around heritability filled me with a looming sense of fear that I might one day experience mental health problems, I did not view my own experience of distress within this category, but rather as intense grief. I subsequently received counselling, which I found to be beneficial, and which also broadened my understanding in terms of how emotional distress could be managed and addressed; my views towards distress were shaped by the receipt of professional help.

A few years later I embarked upon a change in career. I had been working in finance which I did not find fulfilling, and decided that my ideal work would be something that I considered worthwhile and interesting; I

settled upon a move towards the field of mental health, ideally in a research capacity. At that point, I knew nothing of medical sociology, and considered psychology to be the 'obvious' route. Upon discussing my plans with a social scientist, I was introduced to an alternative approach – that of sociology – and considered it a viable alternative. I began a taught masters degree, where I was introduced to the concept of social construction and its application to mental health; my hitherto firm beliefs around the concept of 'mental illness' were called into question. This new perspective impacted upon how I viewed the concept of mental health, and I began to reinterpret some experiences (if not all) through this new lens; I remained cautious as to the boundaries of its application, in awareness of my limited exposure to the subject area. Upon beginning this study, my position was one of a constructionist, albeit not a strong constructionist. Over time, I have encountered more arguments both for and against a social constructionist position. Indeed, not only have I come to be aware of a much greater breadth and depth of argument, but I have also been able to gain greater understanding of my own personal experiences, reinterpreting them through the eyes of a medical sociologist; my lay understanding has continued to be shaped from a range of perspectives and experiences. My overall approach has not changed significantly, although a much more refined understanding of the topic area (and of the boundaries of social constructionism that I have chosen to apply) has been gained. I continue to use social construction as an approach, and apply a weak constructionist (Hacking 2003) perspective, indicating that my own views are critical of medical concepts, and associated treatment approaches, as discussed in the literature review. It is not possible to assess the extent to which my own experiences have shaped my ontology separate to the reading of literature and indeed, the study's findings (for example, that the effect of intense distress itself impacts upon an individual's ability to seek help). Rather, it is more appropriate to illustrate my own journey in this subject area, and concede that any researcher has a perspective, whether insider or outsider, that must be made explicit; my own journey towards this subject area has included a *particular* range of perspectives.

Chapter 4

Lay understanding:

The nature and content of lay understanding and its hypothetical application to help-seeking

This chapter will look at the views of the lay participants to consider their content and what commonalities might exist amongst individuals' views. This is with the intention of shedding light upon lay knowledge and whether this might prove useful for service provision, from the point of view of considering its content, and also its role in the help-seeking process.

I will begin by examining the nature of lay understanding, in order to illustrate that the inferring of help-seeking behaviour based upon a person's lay knowledge is fraught with difficulty; the role of lay understanding is limited. However, it remains a fruitful endeavour to understand more about lay knowledge as this helps to elucidate the social context of which people who might be experiencing distress are a part. In addition, there is value in understanding how individuals prefer to give help to others, and what help they themselves might want to receive. I will also illustrate the content of lay understanding, to shed light on how and when individuals might interpret a person's distress (or behaviour) within a framework of 'mental health'. This provides useful insight into how the boundaries between wellness and illness might be negotiated. These views can then be usefully contrasted with the views and experiences of help-seekers in later chapters.

I will present a description of the data alongside its analysis, and will then consider the data in relation to literature in a separate section entitled 'discussion' underneath the appropriate data. This will be done in each different section of the chapter – the nature of lay understanding itself, how individuals view the concept of 'mental health', what they perceive to be the cause (and any 'cure') and lastly I will consider the relationship between lay understanding and hypothetical help-seeking.

The idiosyncratic nature of lay understanding: biographical and philosophical

When analysing data it became apparent that each interviewee views mental health in a unique way that appears to be shaped by a combination of their biography, their context and their own personal interpretation of these factors. For each participant, the *nature* of their understanding is that their views contain an *internal logic*. Lay understanding makes sense when explained with reference to their experiences, their stated reasoning and the sources of information that they drew upon.

The structure of the interview followed a pattern of asking participants to talk about any formal training or education in relation to mental health, and then to discuss any direct experience of the topic, such as their own experience or that of family and friends, before then going on to discuss their understanding of the topic. Participants therefore frequently drew upon these experiences when discussing their views, and this is to be expected as an outcome of having introduced their experiences earlier on. However, there was frequently a discernible link between their experiences and their views, that is, participants' views appeared to have been shaped by their experiences *to some extent*. In addition, participants frequently drew upon their own experiences to illustrate and support their views. For example, Julia works with youths who are identified as having challenging behaviour; her views around mental health problems are that problems stem from multiple disadvantage, the experience of adverse life events without appropriate support, and having a difficult family background. She frequently draws on her experience of working with youths (some of whom she refers to mental health services) to illustrate her views:

Julia: I think a lot of the people that need this type of help are ... a lot of people that have probably had problems the majority of their lives as well .. it seems to be an ongoing circle all the time I've worked here you know in this sector it is .. it's you know ... it's kids who've been abused ...

Julia draws on her experience of working with young people from difficult and abusive backgrounds (some of whom have been diagnosed as having mental health problems) to illustrate her views; her own views are grounded within her

experience of work. Kate, when talking about the likely causes of mental health problems, draws on her family's experiences to illustrate her views, as well as what she has seen on television and learned from her mother (with reference to witnessing anorexia in a boarding school):

Sue: ok so .. you talked about it being something that's in the brain, so a chemical, do you see it having a biological root or more than one root or
Kate: probably more than one root, again I've never studied this so this is all kind of just my own imagining ... I do think .. an actually chemical thing and that's for a lot of people ... and it's genetic as well thinking this again from Stacey [character from television programme 'Eastenders'] cause I know her mum had it so I think it's probably genetic some of the time but then at the same time I do think it must be events, it was so for my mum, it was an event that triggered it, you know it was her brother passing away and ... maybe what happened in her childhood as well I think it must be .. events must trigger it but I don't think it's a black and white as they say .. oh it's just events or it's just a biological thing, it's probably a combination of the two .. I imagine some people ... well I imagine the same with eating disorders, I guess that can be classified as a mental health iss.. illness can't it .. that probably is .. I'm sure some girls are .. and boys as well .. are predisposed to having eating disorders, but no doubt if you are a girl and going to an all girls boarding school where all the other girls have got eating disorders you're much more likely than if you're in a different situation so .. yeah it must be a combination of the two

There is therefore a strong *biographical* element of lay understanding, and individuals draw upon their experiences to support their views. Views evolve over time as new experiences shape and reshape them; some participants contrasted their views now with their views when they were younger, shaped as they are now with new experiences and maturity, as well as a different context. For example:

Diane: now I feel more aware that .. there's a lot of underlying sort of hidden [emphasis in participant's speech] mental health problems that people aren't aware of really or that don't .. you wouldn't necessarily know .. for sure that someone had a mental health problem whereas I think I used to feel that it was more obvious .. but I think that is a sort of age thing, sort of how people used to view mental health more .. but .. I find that hard to quite define um ... and I think as well when I was younger I didn't really have any experience of anyone having any problems so .. people just sort of got on with stuff .. was the attitude to have really so [...] I think it's until you actually come across a person who has experienced something that .. I mean my niece had a boyfriend who was really nice, chatty person and seemed .. you know comparing him to other boyfriends that other of my nieces had had you think 'oh he's really nice' .. but he would be very hyper and then it turned out that he had bipolar disorder and he had quite an episode at one point but .. in the past if someone had described .. a manic depressive to me I would have thought 'oh that would be obvious to know how somebody is' and I think in that sense .. just being more aware and also that there's not so much stigma to .. I don't think there's as much stigma as there was in the past when people would .. I don't know, not talk about stuff I mean that would be the same for a lot of illnesses perhaps .. and .. that people make more effort perhaps to accommodate people in the community and you know that at one time someone .. I mean he had a very bad episode he had to be sectioned for a while but that would have been like .. in my day [laughs] if that would've been my boyfriend my parent's would have thought 'oh wow' you know that sort of .. it's something that you just couldn't contemplate happening and then ... but that deep down that person was still normal [makes sign for inverted commas] you know ... and I say normal it sounds a bit ..that doesn't sound right but you know I think that in the past that would have been .. you would have felt that .. that there was perhaps no hope for that person whereas I feel that perhaps that there's a little bit more understanding and a little bit more .. sort of hard to express ... acceptance maybe of people

This excerpt shows the combined effect of these different temporal influences – her experiences (in this case, her niece’s partner), maturity and a changing social context – that have culminated in her views evolving to their present state. Understanding around mental health is therefore an evolving phenomenon, one that grows and changes alongside a person’s biography.

As well as deriving from personal experience, participants’ views also appeared to contain an additional dimension that is not easily encapsulated in one word or description, but that could be similar to that of Williams and Calnan’s perceived ‘moral philosophy’ (1996, p.51) that was apparent in their own data. What is apparent in the data is that participants expressed views indicative of an underlying ‘sense of the world’ linking their views to a broader, existential viewpoint in some way. For example, when discussing what services he might use (and therefore which he might not use) Phil expressed a view around psychoanalysis that linked into a broader view about overcoming problems:

Sue: is there any services or other types of help that you would steer clear of

*Phil: uh .. I wouldn’t sort of just run myself to a psychoanalysis off on a whim because I just don’t agree with that to be honest, not just um, you know like in America ‘oh I’ve got see my psycho today’, whatever it is, **no no no** that’s .. **it’s a game** you’ve got to cope with these things yourself you know, you don’t want somebody rummaging around in the corners of your brains just for no reason you know what I mean [emphasis in participant’s speech]*

Sue: [...] so if you were feeling really distressed yourself, is there anywhere that you might seek help

Phil: oh in my situation I’d probably talk to a monk um, because you have dharma, which is .. see Buddhism is not a religion, it’s a way of living and with dharma you have the correct way and the wrong way of doing things and if you speak to the correct monk, not every monk would help you, they’ll give you solid advice and ... how to cope with certain situations if you’ve got a problem with it .. and .. I find that probably would solve my particular things yeah

Phil suggests that coping is part of a 'game' that individuals must play, and that intervention (*i.e.* someone else 'rummaging around in the corners of your brain') is not how the 'game' should be played. His views around his own help-seeking tie in with his Buddhism in line with his 'way of living' according to dharma. This sense of underlying 'world view' does not only apply to religion however, and Michelle provides a different example related to her sense of self as a 'do-er'; Michelle relates this to her childhood and her family members being social workers:

Michelle: I think ... because I've got part of the [psychology] degree knowledge and my mum and brother are social workers they've always been the .. if you came home from school and something was wrong, it was never 'oh no how terrible' it was always like, 'well, why didn't you do that' or like 'do that' I've always come from like a real problem solving family it's never been just sit there and wallow about it, it's like 'do something' so I kind of don't have much sympathy when other people don't do stuff so I'm kind of like 'well why don't you do that' and I think that it's just my nature

Michelle relates her actions towards the experience of problems (including distress) to her 'life view' that she gained through having a family environment where problems were not so much given sympathy as an appeal to action. Her views around mental health problems contain frequent references to the actions of individuals themselves and individual responsibility for one's own well-being. Whether an individual attributes their particular views to religion, upbringing or their approach to 'life', participants' talk around illness action contains some form of philosophical underpinning that coexists alongside their understanding that is derived from experience and education.

Leading on from the above, understanding around mental health can be viewed as idiosyncratic. Participants' views contained phrases that convey a sense of vagueness, alluding to processes they do not understand but that participants still have a sense of. For example, when Sarah was discussing what might cause mental health problems, she said:

Sarah: it could be something really major like it could be a death perhaps or .. an incident or .. something like that .. it could be medical .. so you know .. whatever's happening in the brain goes funny..

Sarah's views around causation included a significant element of 'life problems' as a cause of problems, and the process by which this leads to mental health problems is understood as 'whatever's happening in the brain goes funny'. She employs a phrase that conveys a process she doesn't understand, but that she thinks happens nonetheless. A similar vagueness is employed by Anthony who views life problems as being a major cause of mental health problems. He employs the term 'rupture' in someone's life to capture a process by which a significant and traumatic event that causes a rupture in the person's life, might cause a similar rupture in the mind; when asked to speak more about causation he responds:

Anthony: there are people who maybe are born with some sort of mental defect um ... hereditary things um I imagine exist as well but I don't know I think for a lot of people maybe it is things that happen .. some sort of trauma they experience make them uh, kind of have some sort of malfunction in the mind

Again, Anthony uses a phrase that is vague in its description 'some sort of malfunction in the mind' but nonetheless describes a process he perceives as taking place that marries the social to the biological. Participants frequently spoke about a mixture of causation, from social causes through to biological and genetic explanations, and these combinations are able to sit alongside each other through reference to different unknown processes. Participants' understanding included contradictions, and combinations of different paradigms fused together to form a whole that was coherent to the participant. Participants drew from different sources of information relating to mental health, for example: workplace training, education, television, films and the internet (to name but a few). This included current campaigns addressing the prevalence of mental health problems within the population, a campaign that was quoted by a number of participants:

Kate: I was in the waiting room and there was like lots of posters and stuff, and there was one and I remember the statistic I thought it was amazing.. it was Ruby Wax on the cover ... I might have got this slightly wrong now .. one in five people suffer from dandruff, one in four people suffer from depression and I was like 'oh my, that's a huge amount, one in four people' ..

Understanding is therefore derived from a variety of sources, and participants are likely to reflect their differing exposure to these different sources. As a result of the various different influences that shape lay understanding, participants' understanding is highly idiosyncratic; whilst there are commonalities that are addressed below, there are also many differences, with each participant's understanding containing an 'internal logic' when viewed according to their experiences and viewpoint.

Discussion

The findings described above echo the literature around the *nature* of lay understandings. Blaxter (2010) points out that lay knowledge is partly shaped by a person's history, and data in this study is similarly grounded in individuals' biographies. Where participants' views appeared to have been shaped by their experiences *to some extent*, this also fits in with Bury's (1997) description of lay knowledge as being shaped by the health experiences of the members of an individual's community. Bury (1997) describes a lay epidemiology that individuals draw upon, when thinking about health and illness. As mentioned in the literature review, Bury points to the 'loosely organised and fluid character' (Bury 1997, p.31) of lay views that cannot be placed within a 'simple explanatory framework' (Bury 1997, p.32), and the data provide support for this. He also describes 'cultural repertoires ... in the form of 'pull down menus'' (Bury 1997, p.32) that individuals draw upon to explain their health beliefs, a stock of perspectives that reflect the context and also the history of individuals. Bury's work points to the inherently biographical and contextual nature of lay understanding, in line with the idiosyncratic understanding found within this study. It is clear from the data that contradiction within views (that is, views that may contain 'contradiction'

when considered from a particular theoretical perspective), and mixing of paradigms, is not problematic in the eyes of participants. The data points towards the likelihood that individuals are able to live with contradiction within their understanding, and that behaviour relating to illness is acted out in accordance with the sense that it makes to the individual in line with their understanding – however idiosyncratic this might be when compared to a professional paradigm. Hypothetical illness behaviour will be discussed in more detail below. An interpretivist framework (as supported by Dingwall (1976)) appears to be the most suitable in terms of accessing lay understanding; individuals' health beliefs make sense to those individuals. Dingwall (1976) stressed the importance of understanding lay epistemologies. He suggests:

A prime task of the medical sociologist is, then, the study of how both lay persons and 'professionals' theorise about the human body and its operations and management. From the point of view of the sociologist, all such theories have an equal epistemological status. Taken in context they are all equally sensible, rational and reasonable. This does not commit us to regarding them as equally efficacious in achieving actors' goals (Dingwall 2001, pp25-26)

Thus he argues that lay understanding should be viewed as rational, when taken in context of its deployment, and the data is supportive of this viewpoint.

Individual responsibility is a common feature in lay understanding (Blaxter 2010), imputing blame and moral responsibility to individuals who become ill, and this is evident in some of the interviews. This touches on discussion of the moral dimension (Blaxter 2010, Radley and Billig 1996) of talk around health and illness; whilst this did appear within interviews, it did not form a significant theme, and this aspect will not be further addressed here, suffice to say that when discussing illness, Blaxter (1990, 2010) points out that the degree of blame attributed to an individual (for their illness) varies according to the type of illness being discussed, and its proximity to the speaker's own life.

How do individuals view mental ill health? Negotiating continuums between ‘normality’ and the ‘strange’

Having discussed the nature of lay understandings, I will now turn to the content, and will then conclude with a discussion of what relevance this content might have. The interview schedules, as mentioned in chapter 3, focused on attempting to obtain participants’ responses around the following specific aspects relating to mental health: defining ‘mental health’ and mental health problems; what might cause mental health problems; what might improve them (inclusive of treatment, but without applying a ‘treatment’ framework from the outset); where participants might seek help, or advise seeking help; whether there were any specific ‘triggers’, signs or thresholds of distress that might trigger seeking help (or advising seeking help); what help do participants think is available. Latterly, the schedule evolved to include how participants would feel if offered psychological therapies, although responses to this are considered in chapter 6. The following section provides an analysis of the pertinent themes that arose from these areas of questioning, and culminates with a discussion of the utility of understanding lay knowledge.

Defining ‘mental health’

Participants were asked to define the term ‘mental health’ to see how it was conceptualised. There was variety amongst definitions, and three types of definition were found amongst the lay group:

1. *Mental health as a continuum relating to well-being: a continuum between good and bad mental well-being, for example:*

Sue: how would you define the term mental health

Michelle: um .. I guess it would relate to kind of like cause it’s not just a bad thing, it’s just the state of your mental wellbeing and behaviours at any given time, I think that’s how I’d define it, so you could have good mental health or bad mental health, I think

2. *Mental health as a continuum relating to well-being, and including the brain and the intellect: a continuum between good and bad mental well-being, also*

encompassing difficulties associated with changes in or damage to the brain (such as Alzheimer's) and intellectual difference (such as autism), for example:

Sue: how would you define mental health

Dennis: what from being fully mentally healthy and ...

Sue: yeah

Dennis: somebody like me .. who's just a little bit mad [laughs] ... well you get like the top end and then you get somebody who .. who's old maybe, older who's going to get dementia and Alzheimer's, forgetfulness and then you get the people in the middle with the other problems that I spoke about you know .. self harming, unstable, I think a lot of it's down to .. stress .. modern living .. um .. some people can handle it some people can't ..

Sue: and when you said you've got the top end, what do you mean by the top end

Dennis: well, somebody who would be classified as normal

3. *Mental health as a category of illnesses:* this includes a range of different mental health problems, focusing only on the notion of disorder (*i.e.* excluding positive well-being), for example:

Sue: how would you define mental health?

Anthony: um would it be some kind of illness – I know that's kind of a big word but .. in the mind so .. something that's stopping them functioning in the mind in a normal way, normal being in inverted commas so ..

Sue: ok so .. do you know of what you might consider a cause of that

Anthony: a cause of a mental health .. uh .. probably some sort of like rupture in .. in someone's life could cause them to become mentally ill I suppose

The most common response amongst the lay category was the *third*, that of the notion of disorder alone. When speaking to the recent help-seekers, participants'

responses included a fourth definition, which was the most common amongst help-seekers:

4. *Mental health as some kind of fear/vulnerability that everyone has to some extent:* Mental health (or the potential for mental ill health) is something that affects us all, for example:

Sue: how you would define the term mental health ... and what you think about it

Sally Anne: how would I define ...

Sue: mental health

Sally Anne: my mental health or in general

Sue: in general yeah

Sally Anne: oh I don't know, I don't know mental health in general I think we've all got mental health issues haven't we ... even Tony Blair had mental health issues ... you know .. I think we've all got mental health issues you know what upsets one don't upset another ..

Mental health is defined as an all encompassing term by those who view it as a continuum (the first and second definitions; the 'well' are included alongside the 'ill') and by those who view it as an inevitable part of life (the fourth definition; *i.e.* that it pertains to vulnerability and that everyone is vulnerable or struggles in some way). The most common definition amongst the lay respondents is one that defines mental health as a broad category relating to illnesses or problems that are solely negative (*i.e.* this is a separate category from 'wellness') and applies only to a specific group of people who are experiencing mental health problems.

The excerpt given above to illustrate the third definition, *mental health as a category of illness*, shows the participant conflating the term 'mental health' with 'mental illness'. The example given above was not an isolated case, and it must be borne in mind that conflation of terms occurs. For this reason, there were times when more than one term was offered, in order to see if differences existed in how they were understood (*i.e.* after defining 'mental health' participants were then asked to define 'mental illness'). The terms

‘psychological distress’ and ‘emotional distress’ were also discussed alongside ‘mental health problem’ in order to probe where differences in perception might lie between the concepts. This was initially to discover whether extreme distress was viewed differently to ‘mental health problems’ or not. Responses suggest that the two are frequently perceived as one and the same, although when discussing behaviour that seemed ‘irrational’ or difficult to understand, this was viewed differently to ‘distress’. However, this is not to say that participants necessarily view extreme distress as a ‘mental health problem’, but rather that the term ‘mental health’ may be used to communicate, describe and articulate extreme distress and misery. This does not imply that individuals necessarily perceive that extreme distress is a ‘medical’ problem. One example of this occurred during an interview with Sadie, after she described a period during which she thinks she suffered from depression:

Sue: so um, if we look back at um .. defining mental health then so .. you’ve experienced what you’d call like a touch of depression but you didn’t think it was really really serious

Sadie: severe yeah ... because I’d never felt it before, but now I’ve been down in the past, I know that yeah, I think I was depressed then, to not get out of my .. I used to stay in bed all weekend and .. wouldn’t eat drink or anything yeah I know I was .. I did suffer a little bit of depression then I do believe I did yeah

Sue: so um what do you think causes depression or other mental health problems

Sadie: it’s different for everybody though isn’t it .. some people can deal with things differently like .. to me it would be .. my relationship breaking down that caused me to be depressed ... um money ..pff [sigh / exhalation] I think that’s a big one isn’t it .. sort of losing your house maybe losing your job, work, pff, life in general can drag you down can’t it, but I would say mainly .. you know, money, probably not happy in a job, um relationships, I would say that one would probably be .. ‘cause the majority of my friends when they’ve been down it’s through .. ‘cause of relationships so to me I would say .. relationships..

Here Sadie talks about being ‘down’ and the different causes of this, indicating that she is talking about misery and not necessarily a definable medical diagnosis; she refers to her own period of depression (as she terms it) and then when asked to discuss the causes of depression, she appears to revert to discussing unhappiness, and being ‘down’. It appears that she views the two as one and the same, although potentially at different places on a continuum. The boundaries between what participants viewed as ‘misery’ and what they viewed as a ‘mental health problem’ were potentially moveable, with language drawn from one to refer to the other. So, whilst participants may have viewed mental health problems and extreme distress as interchangeable, this may partly reflect the language used to articulate distress. Participants’ views about the differences between the two will be discussed more below.

Participants referred to a broad spectrum of problems that fall within the remit of ‘mental health’. When defining what might fall within this remit, participants’ talk took three main forms:

- *specific diagnoses* such as schizophrenia
- *how distress might be experienced/manifested* such as an inability to ‘cope’
- *observable behavioural difference* that include a stereotype of ‘someone crazy walking along the street’ (Diane)

Whilst behavioural ‘stereotypes’ were referred to (such as that just given by Diane), participants’ talk tended to focus around depression and problems they have observed and experienced within their community; behavioural stereotypes did not form the majority of what was discussed.

Identifying, or categorising, ‘mental health problems’

As mentioned above, the concept of a continuum between good and bad mental well-being was discussed when defining the concept of mental health. Participants frequently problematised the notion of normal (which was often accompanied by a gesticulation indicating inverted commas: ‘normal’) and discussion around defining mental health overlapped with the idea of categorising, or *identifying*, mental health problems. ‘Mental health problems’,

as a category, were seen to encompass extreme distress (such as extreme sadness) or behavioural manifestations, both of which are placed on a continuum with 'normal'. Participants discussed the nuances between 'normality' and 'difference', exploring the boundaries and describing one with reference to its comparison with the other.

As mentioned above, in defining the term 'mental health', participants frequently referred to examples or experiences, and thus defined the concept with references to *identification* or *interpretation* of what they view as mental health problems. Discussion naturally moved towards how or when individuals might interpret someone's distress or behaviour through a framework of 'mental health' or not. The following therefore illustrates when and in what circumstances individuals used a framework of 'mental health' above a different explanation; the different examples comprise the *nuances* of what individuals said, and so not all examples applied to all participants, however they all show different ways of negotiating between 'normal' and 'worrisome'.

A common assessment of whether 'mental health' was an appropriate label was not necessarily the presence of distress or any kind of compulsion or behaviour in itself, but the extent to which a person's everyday living is affected by such issues. For example, Kate provides an interesting illustration of a continuum, in relation to experiencing compulsions:

Sue: so how would you define the term mental health

Kate: oh crikey ... I guess when there's something ..with a person and it's not a physical illness it's a .. you know it's something in their mind so it's affecting their day to day .. being but in sort of like how it's .. well affecting their mental state sort of thing I know about my cousin's OCD .. even though he's a perfect specimen of .. well he's really healthy and everything but he can't leave the house without flicking all the light switches or something like that so I think .. when it's bad enough it's actually affecting your day to day being .. I don't have an OCD but I do have a tendency sometimes to be like .. oh well if I tap the table ten times I'll do well in my exam .. but that's so rare in occurrence it doesn't affect me on a day to day basis so I don't think I suffer from it but I think when something's actually having ramifications every day ..

The boundary at which distress and/or unusual behaviour becomes a ‘problem’ is when it affects daily living, and the *extent* to which it affects daily living. Indeed, Anthony provided a different interpretation of ‘normality’ and ‘difference’ that allows for greater inclusion of difference within a framework of normality. Anthony discusses the importance of viewing behaviour in its context:

Sue: what if any sign might uh move you towards suggesting someone seeks help?

Anthony: [...] definitely behaviour out of the ordinary um .. yep but I suppose you would need to see some lots of behaviour in context as well .. of what they're maybe going through at the time so lots of people .. I know lots of my friends are all really stressed at exams and people are doing really strange things that maybe they wouldn't usually do um but I don't think they're all mentally ill I just think they're stressed and um ...behaviour kind of does change based on context but .. maybe outside of that context it would be a bit strange but inside it it's ok

The above two examples show participants grappling with defining or identifying whether ‘unusual’ behaviour could be constituted a mental health problem, and suggesting where a boundary might lie. There is a common view that *some* unusual behaviour is ‘normal’ and especially in specific contexts; there is a threshold at which point a person’s behaviour becomes too unusual to be accounted for within a ‘normal’ framework, and this includes an assessment such as the level of interference with a person’s daily life.

Diane discusses a slightly different point relating to the acceptance of ‘unusual’ behaviour, and suggests that whilst it may be termed a ‘mental health problem’ (if indeed the behaviour is labelled) it is not considered something that is a ‘problem’ if the behaviour is *benign*:

Diane: sometimes you can recognise that someone has .. does have a slight mental health issue if you were to define it as that but it's ... it becomes part of who they are and as long as it's not harmful in any way [laughs] then you sort of let them get on with it... and I don't think you

can help .. it's not that something can help it's more you feel that perhaps the other .. you as a person experiencing their behaviour sometimes are finding it more worse than they do being themselves really ...

The above excerpt indicates that the identification of or defining of a mental health problem is in part mediated by whether there is any potential for harm (to the individual or to others). The notion of 'normal' is therefore viewed as expansive and includes unusual behaviour based on whether it is benign, whether it is out of context and the extent to which it interferes with social functioning.

Moving away from a discussion of more subtle nuances between 'well' and 'ill', there were examples of when individuals would more clearly apply a framework of 'mental health difficulty'. One way in which the threshold between 'well' and 'ill' was perceived as recognisable related to being able to discern specific behaviours, or changes in behaviour. Participants viewed a significant change in behaviour as indicative of a problem, as was the presence of self-injurious behaviour, significant changes in eating patterns and behaviour that was not intelligible within its context. In addition, behaviour that involved withdrawing from social activities and from other people was also viewed as indicative of an identifiable problem. Some notion of normality was ever-present as a yardstick against which deviation could be measured; difference was interpreted with reference to different mediating factors of potential harm, the extent to which an individual is able to engage with their daily life and obligations, the context of any change, and the extent to which their behaviour is intelligible and/or worrisome to the onlooker.

Difficulties in interpreting one's own distress: the importance of other cues

Whilst participants discussed potential ways of differentiating between the experience of distress (and the presence of unusual behaviours) and 'mental health problems', some participants also expressed continued doubt as to whether it would be possible or feasible to recognise this within oneself. Thus, the presence of specific cues was likely to help in identifying something that was 'problematic' from something that was not. For Michelle, Anthony and

Diane, these specific cues were relating to the intervention of other people. For them, the act of seeking help was presumed to be less clear-cut, questioning whether the experience of distress would compromise their ability to know when best to seek help, or indeed their ability to engage in the act of seeking help for themselves. Michelle and Anthony in particular discuss the likely difficulty in understanding that something was wrong with themselves; that is, they point to the likelihood of a lack of perspective or insight. In Michelle's example, she suggests that the experience of mental health problems might in itself create a lack of insight; she has seen two friends experience some form of psychosis during which they experienced delusions, thus her views around a lack of insight is likely to be derived from this experience. Anthony suggested that it would be difficult to perceive changes within oneself, and that another person (who has a more 'objective' viewpoint) would be able to discern changes more easily. For Diane, she simply felt that if in a distressed situation, a person may be less able to help themselves than usual.

Thus participants in the lay group speculate whether the act of seeking help is inhibited by the experience of distress and the potential difficulty of interpreting problems from the inside. In addition to help from other people, physical symptoms were also perceived as a clear indicator that something is 'wrong'. Indeed, Sarah, a teacher, tells her own story of seeking counselling through her work, which was only initiated after a colleague suggested she do it; she was experiencing problems after a traumatic incident on a school excursion to another country:

Sarah: I knew I wasn't right, but I didn't know what was wrong .. if that makes sense, you know, crying a lot, and although really I should have had time off work initially and it wasn't, you know it was straight back to it, you know almost put under the microscope and I think I wasn't allowed the time to sort of process it correctly and then it was sort of straight back into a manic environment and then .. I can't think who it was.. it was one of my colleagues, who said Sarah, have you thought of talking to anybody and I said 'well who' you know and she went 'well you can through' cause she's going to somebody here at college, and she

said 'well you can either speak to somebody through college or they use independent providers for staff' and I thought 'oh well I'll give it a go'

Sarah speculates that had she not been advised to speak to a counsellor, she would have waited for the summer holidays to see if a long time away from work might help. Indeed, she said that for herself, she would only seek help from a GP if her distress culminated in her experiencing physical symptoms such as sleeplessness or headaches, because these *physical* signs were an indication that something was *actually wrong*. Kate reflects on the difficulty of deciding at what point help should be sought, as she would wish to avoid 'making a fuss over nothing':

Kate: I do think that is one of the biggest challenges like .. oh when is it the right time, when is it 'I'm just causing a fuss over nothing' or when is it like ..it actually is a real problem...so .. yeah to me it would just have to be when it was stopping me doing things that I enjoyed and wanted to do and something that was actually playing around on my mind like you know, to the point where it was like really affecting me .. yeah I think that would be the point where I would ... think .. ok, just talking to somebody, one of my friends won't be enough I need to actually go and get some professional help about this ...

Participants speculate that it is actually difficult to feel confident in knowing when a specific experience warrants (and might benefit from) help; for this reason, bodily signs are a more recognisable indicator that something is wrong (and that a doctor may be able to help), alongside the intervention of family or friends.

Discussion

In relation to defining mental health, the continuum-based definitions encompass notions of *well-being*. The first definition focuses on well-being specifically, as a continuum from good to bad. The second definition also includes deterioration of the brain, and difference in intellect (as examples) and thus is more wide-ranging than a focus on well-being. It relates to the brain

more generally, including its relation to mood well-being; it encompasses *mental function*. The third definition classes mental health as relating to a specific category of illnesses only; rather than encompassing mental well-being, the definition excludes positive states, and refers only to experiences that are in some way ‘disordered’. The fourth definition neither refers specifically to well-being, nor to illness, but rather to a vulnerability of some sort that is in everyone; phobia and fear are given as examples. There is variety in what the term ‘mental health’ means to individuals.

When discussing mental health *problems*, individuals talked about extremes of emotion and of behaviour. Participants’ talk addressed nuances of ‘normal’ (or ‘unproblematic’) and ‘problematic’. Negotiating the boundaries between the two entails an interesting process that takes into account context and severity; the different examples given reflect different participants’ responses – no one participant expressed all three nuances. But the examples do show the breadth of how ‘normality’ and ‘difference’ might be negotiated, seeking to understand the person and assess their problems before viewing such problems as mental health difficulties. This process enables normalisation of emotions and behaviours that are either potentially explainable, or ‘benign’; only difficulties that are considered unexplainable and ‘worrisome’ are considered appropriate for seeking help. Of course, the boundaries of what is considered explainable or worrisome are inherently socially defined, but nonetheless serve to provide some measure of assessment of whether someone’s emotions or behaviours are a ‘problem’ or not. Thus, whilst normalisation is viewed as inhibiting the seeking of help – indeed Zola (1973) argues that the most common response is *delay* of help-seeking – Heath (1999) argues that it may also serve to keep distress that is *manageable* (or that may be self-limiting) outside of formal care. The data provide some insight into how individuals might negotiate a decision to seek care (or to advise the seeking of care). Indeed, when discussing the ‘clinical iceberg’ that is said to exist, it is important to consider what extent this ‘iceberg’ might encompass difficulties that are viewed as ‘manageable’; whilst Heath argues that the process of normalisation is often beneficial (in that individuals may go on to recover without medical intervention), normalisation may also delay seeking of help for others. Intervening in this process (by attempting to redefine what

‘appropriate help-seeking’ is) may have both positive and negative consequences by shifting the level at which distress is defined as being ‘normal’.

Certain aspects of the findings reflect what has already been discussed in literature around lay understanding of health more generally. In terms of individuals’ *talk* about mental health and when a label might be applied to an individual’s experience, participants discuss the idea of being able to achieve one’s daily obligations and of being able to cope. These are themes that chime with the findings of Blaxter (1990) – that maintaining ‘functionality’ is a salient indicator of wellness versus illness. The work of Pill and Stott (1982) found that ‘being able to cope’ is another key indicator of whether a health-related issue is constituted as problematic. Zola’s (1973) ‘triggers’ appear salient with regards to how individuals categorise a person’s experience as problematic; the following of Zola’s triggers were present in the lay discussions: ‘the *perceived* interference with social or personal relations; sanctioning; the *perceived* interference with vocational or physical activity’ (Zola 1973, p.683, emphasis in original), comprising three out of five of Zola’s triggers. In relation to how to negotiate what is ‘problematic’ and what is not, some participants did express that physical symptoms provide a clear signal that something is indeed ‘wrong’, and the salience of physical symptoms has been found in previous work (Pill *et al.* 2001, Prior *et al.* 2003). Deciding when to categorise ‘normality’ or ‘abnormality’ in relation to behaviour and emotions is a process fraught with difficulty and implications, and physical symptoms provide an anchor to something ‘real’ (and a cue to action). Somatisation is therefore likely to remain a difficulty within consultations, as physical symptoms may provide the bedrock that a problem actually ‘exists’. In addition to physical cues, some participants suspect that it would be difficult to know in oneself if there was actually some form of ‘problem’, and therefore the intervention of others is perceived as potentially *necessary*. This provides the sanctioning that Zola (1973) refers to, but is also seen as potentially providing insight that an individual may have difficulty in achieving for themselves.

The language used to discuss mental health reflects the use of terms that are drawn from professional discourse; indeed, use of the term ‘mental health’ in the study might set the scene for this process. The experience of strong

emotions may be viewed through a professionalised discourse in line with De Swaan's (1990) notion of proto-professionalisation. But, as I will discuss below, this does not necessarily mean that a medical framework is viewed as the most appropriate, or that medical treatment is desired; the use of terminology implies that it has become a way of articulating emotions, but this does not mean that a desire for medical treatment has also been internalised. I will discuss this in more detail below after I have presented what individuals believe to be useful in the event of mental health difficulties.

This section provides original insight into the how individuals negotiate boundaries between 'well' and 'ill' in a contemporary context. Whilst they confirm previous findings relating to the salience of coping and functionality, this section provides deeper insight into how these are negotiated, and the extent to which individuals tolerate or do not tolerate problems in the absence of confirmation that a 'problem' actually exists.

Understanding around mental health: causes, cures and 'consistency'

What 'causes' mental health problems?

In terms of causation, participants spoke about a range of causes from biological to social explanations. The causes that featured most frequently in participants' responses were:

- Life problems (varying from 'normal' life problems such as relationship or financial problems, to extreme circumstances such as childhood sexual abuse)
- Hereditary / genetic explanations
- Toxic or harmful social environment
- Biological (including brain injury, hormonal, and 'unspecified')
- Individual coping style

Some participants talked about the hereditary nature of certain illnesses such as bipolar disorder, with reference to the character of 'Stacey' from the television programme 'Eastenders'. However the most common perceived cause of mental health problems was relating to *social causes*. This took various different guises; some participants referenced traumatic events that are

considered unnatural to a 'normal' life, such as child abuse, tragedy through early bereavement or other such interruption in a perceived 'normal' life. Dennis talks about a friend of his who was recently hospitalised following an episode of self-harm and he mentions his friend's traumatic upbringing as causing her current problems:

***Dennis:** she's a friend of me and my wife [...] we've always thought that she was a bit .. how can I put it .. unstable [...] she's been unstable for a long time ... uh she had a really **poor** upbringing, there was a lot of uh how can I say ... abuse going on within the family uh [...] most of the time she's fairly stable but apparently she's just .. blown [emphasis in participant's speech]*

For some, these events occurring in childhood would constitute a pivotal factor, for others the occurrence of adverse events in adulthood might also result in a person having problems triggered by such events. The idea of 'trigger' events was also common in itself (these are to be differentiated from Zola's (1973) 'triggers' to seeking help); either that a person was fine until they experienced an adverse trigger event, or that a person may be susceptible to mental health problems but that the triggering event itself is what caused the problems to emerge (the idea being that a person may also have *not* had mental health problems, if the trigger event had not happened). For example, Nell recounts the story of a friend who experienced mental health problems:

***Nell:** I think in her case it was set off by sort of a broken affair with a man because as far as I'm concerned up to that point .. I mean she was a very intelligent woman she held a responsible job .. you know she was good company .. and then she met this particular man and she was absolutely .. and this was fairly late in life she wasn't a young woman .. but she was very very taken and there was then some sort of trouble with the daughter she couldn't get on with and in the end it finished and I think she was devastated by that .. whether that started things off I don't know but I do know that that happened not too long before ..*

These participants' ideas therefore show an interaction between environment and a person's mental health, including in conjunction with a biological predisposition. 'Normal' life problems were also discussed (for example problems in relationships, and financial difficulties), causing problems where cumulative or simultaneous in particular. Whilst there was a significant emphasis placed on a person's social world, participants did also talk about biological predispositions that could not be avoided, and that some mental health problems might arise regardless of a person's environment.

A different perspective relating to the role of social causes in mental health problems, was that problems might develop depending upon the resilience or the coping style of the person experiencing problems. In this scenario, more 'normal' life problems (including a vaguely defined 'hard life') might trigger mental health problems in some but not others, depending upon that person's individual attributes. In these instances, participants talked about coping styles, frequently mentioning their own ability to cope, or methods of coping, and how they might differ from someone who does not cope. For example:

Sue: when I say mental health to you what do you think of?

Phil: I think ... I had a um tough upbringing and I found you either cope with it or you don't and um .. yeah I coped with it .. I find that things happen where people might sort of start getting "oh no, what are we gonna do" and I think. .. calm down you know, we'll find an answer for it and I don't like to make problems out of things I like to be a bit more positive about it and that's the difference between .. people having mental problems and people not having mental problems, because people who find everything's a problem, everything's an obstacle and something, can snap sometimes and then maybe they .. find life difficult and um sometimes they get a bit of help and sometimes they don't but ...

Phil suggests that mental health problems are related to coping style and the attitude that a person has to dealing with problems, illustrating his own attitude of remaining positive as being helpful. Dennis puts forward a similar view; although he talks much about biological causes (specifically, he has a parent

who has dementia), and about traumatic events as affecting people, he also links ‘worrying’ to mental health problems:

Sue: have you ever felt at a point within yourself that you’ve been worried about your own mental health or your own levels of distress

Dennis: ... mmm not really ... I’ve had worries but .. uh .. no, never really had an area where I was worried about my mental health no .. I’ve had stress problems and worry problems .. it’s usually about other people ... I worry about my wife a lot [mentions health problems] but that’s another matter [...] if I let it, I could let it worry me .. and then I would have a few problems but as I say with mental health, I’ve seen what can happen to other people, the stress of modern day living is ... it’s a big factor .. a lot of people dismiss it but I could get stressed out over a lot of things but I don’t .. if I start worrying about it then I shall start slowing down, not doing things and then I could be ill myself so I just let it go over the top ..

Thus excessive worry, derived from everyday life, can lead to mental health problems if not kept in check; Dennis talks about letting problems ‘go over the top’ of him, and the need to not take on other people’s problems, thus his coping style plays a big role in whether life problems might lead to mental health problems. Worrying – and in particular, where this could be avoided – is perceived as a potential cause of mental health problems, and something that an individual has control over. Anita discusses her own coping style as being ‘good’, in coming to terms with bereavement following the death of her child:

Anita: you know in the end I suppose ... I’ve just got a good coping mechanism touch wood, that you know I can manage to get through it without resorting to ... I’ve just had sort of support network in terms of my friends and other people like that that I can talk about it and I can talk about it I think a lot of people, they go through bereavement or other things.. bottle it all up and therefore they can’t talk about certain things and that’s where a lot of your .. you know .. psychological things might happen [...] I’m talking about bereavement but you know whether you

accept it and if you accept what's happened you can move on and some people can't accept whether it's any kind of like separation or whether it's .. a bereavement, whether it's something else that's happened in their life if you can accept it and move on .. you learn to cope, however you cope whatever mechanism you have um.. some people can't and so therefore they bottle it up and they can't talk to anybody and therefore that's.. might ..cause all these other problems with.. you know, for them

Anita talks about her support network and her own coping style as helping her to avoid her distress becoming a 'psychological problem'.

Bearing in mind that individual understanding is highly idiosyncratic, participants each held views that are discernibly different from one another, based upon their experiences, education and individual 'philosophy' mentioned above; given the idiosyncratic nature of understanding, the commonalities described above are indicative of pervasive views that may frequently be drawn upon when considering action. Whilst biological factors, including hereditary, were mentioned, a person's social world (and their background) were seen as playing the most significant role in relation to the development (or not) of mental health problems. This had different permutations such as the idea of trigger events (either on their own or interacting with biological predispositions), normal and/or adverse life events, and individual coping styles; the emphasis is upon social factors, with biological and psychological factors also playing a role.

What 'helps' mental health problems

When discussing what might help mental health problems, participants discussed medical and non-medical resources. I will discuss broadly what individuals think helps mental health difficulties, including *broader* views on medication and counselling. However, participants' specific expectations of GP help will be discussed in chapter 6; this will be alongside the medical response that help-seekers received, as it is pertinent to compare 'expectations' with the realities of service provision. This section will therefore address what participants perceive to be helpful in ameliorating mental health difficulties,

and specific expectations of care will be addressed in chapter 6 (where different).

Participants frequently discussed the importance of support networks, and the support of friends and family; the receipt of support from others helps individuals to not feel alone with their problems. Anita, when discussing her own experience of bereavement, revealed she had been to see her GP around the time of her child's death and was offered antidepressants by her GP; she spoke about how for her, the most important thing was to find someone else who had suffered a similar loss, and find out how they coped. She says:

Anita: um, well I'll be honest you know my daughter died um she was ten years old [describes circumstances of daughter's death] you know it was trying to think - oh my god what did this friend whose son had also been had been involved in an accident you know they were sort of the closest people that .. I could relate to.. yeah they'd been through a similar thing where their child's been hurt or something's happened to their child so ... and that had happened like a year before this had happened to us so ... It was like getting advice from them and you know.. knowing then .. how they must have felt at that time because at that time when they were going through it I didn't really realise the impact that it can have on a family and the .. the whole sort of you know uh... implications of that and how they might have coped with it so.. I sort of looked to them to .. you know get advice um.. and ...who else, I went to my GP obviously um... but I didn't find that useful at all because I think [laughs] you know they've got ... they're not really ... again unless they were in that situa.. I think it's very difficult for people unless you're in a situation ... it's very hard to um..give advice ..

Sue: so ... do you mean in term.. are you meaning your GP there in particular um do you mean that because he hadn't experienced the same as you he couldn't .. help you ...

Anita: I think it's more clinical for them isn't it

It is pertinent to note her expressed wish to find someone else who has experienced a similar loss, to help her come to terms with her own distress. She

views her GP's response as 'clinical' (she later discusses their role in 'clinically' managing problems), and she did not feel this response was appropriate for her because what was wrong was not a 'clinical' issue. Thus, the nature of her distress was not congruent with the GP's response. Julia talks about how she helps the parents of the youths she works with. Frequently the parents struggle to cope with their children's behaviour and become extremely distressed at their difficult and enduring situations. She describes a practical type of help that she offers:

Sue: You talk quite a lot about the mental health of the children or youths but how about, what is your experience of parental mental health?

Julia: I suppose a lot of that as well Sue is to do with being a parent myself. So you know, I've got 3 of my own [...] Basically I've been very lucky, none of my youngsters have been in trouble and things like that but I still had the stress of bringing up children and how difficult it is sometimes to get them there so I'll just talk to them [parents] or tell them what it was like when mine were little. And it's just making them feel as though they're not rubbish parents because they can't get them to do this - it's to make them feel good about themselves. 9 times out of 10 because I think a lot of them think they've failed -and they've not failed- they just might need to try a different approach [...] I think instead of sort of saying 'you should do this' I sort of play devil's advocate and say 'oh, you know when my kids did that' - they've not done it because I've been very lucky with all my 3 - 'I tried this' and I'll try and get round it that way. Do it that way so as not to make them feel bad parents really, which they're not, they've just got difficult kids.

Sue: And to make them feel that they're not alone as well

Julia: Exactly and the thing is a lot of it's blamed on the parents [...] a lot of parents out there [...] are trying their best [...] A lot of the time it's not their fault because they really don't know what to do and that sets them off then, getting stressed and upset and lots of other things happening within the family

Sue: So you give them practical advice on how to try things.

Julia: and I pretend I try them, I think it works that way.

Sue: It sounds like it does

Julia: it does actually Sue because then they don't feel stupid, inadequate.

Julia talks about giving parents practical advice on how to cope with their children, a problem that she says can frequently lead the parents to reach the 'end of their tether, literally a bit of a mental health problem' (Julia). Her advice related to practical ways of managing the cause of their distress, and she tells parents that these are methods she has used herself, to make the parents feel as if they're not alone in having these problems. Whilst this is not the same as Anita's experience, there remains a common thread of receiving practical advice from others with similar experiences; such help carries practical coping advice, as well as reducing a sense of isolation in having those particular problems, and this is a sentiment that is echoed in chapter 6. The importance of having one's problems understood was emphasised.

An emphasis on 'practical' solutions may also underlie what individuals perceive to be beneficial in ameliorating distress; when discussing providing advice and help to others (who might be experiencing extreme distress), participants focussed on giving advice relating to the problems underlying any distress, as opposed to distress itself – dealing with the 'cause' of the problems as opposed to the 'consequences' or 'symptoms'. This appears to be borne out of a sense of practicality (that is, removing the cause of distress will remove the symptoms), but may also be due to reluctance in labelling mental health problems as such. It is more comfortable for participants to address the practical problems in a person's life, than to address any resulting emotional difficulties. In addition, participants felt comfortable providing advice relating to issues they 'know about' (financial worries, relationship breakdown, bereavement) as opposed to the area of mental health which is a more 'medical' issue. Anita evidences concern about helping others and of any responsibility that is associated with providing help:

Sue: have you found yourself in a position where you have been giving advice about distress in particular

Anita: ... um... well...(pause)... it's very difficult to give .. I find it difficult to give advice sometimes because I don't know ..different people, like I

say, take it different [...] I'm always a bit hesitant about giving advice to people because I don't know whether what I.. what I think is right might not be right for that person and in a distress situation like you said, I'm not quite sure, unless you've been in that situation I'm not quite sure what other factors that that person has got that's affecting them – they might only tell you about one factor but in actual fact there may be other things that are going on around in their life that might be more important to them, and so therefore, you know, you could give them advice about that particular thing but that could influence other things as well

The giving of advice to a distressed individual is potentially fraught with responsibility, and participants express a preference for areas that they feel they 'know about' (*i.e.* the practical matters that may be causing distress), although Anita points out that this may still have negative ramifications.

Isolation and loneliness are frequently perceived as likely to worsen any kind of mental health problem and so the converse, meeting others and forming (or drawing upon existing) relationships, is seen as highly beneficial. This is seen to provide practical help to individuals, emotional support, and may also help individuals come into contact with services at a time when they might be unlikely to do so for themselves (as discussed in the section above). Diane mentioned the importance of informal support in helping people to access more formal support:

Diane: I think it's much easier if you've got some sort of help in the background as well from someone else .. because I don't think the person who is suffering is quite in a situation to go looking for that help

Whilst practical support is valued, the emotional support that is afforded by friends, family and other community members is viewed as the most important benefit of having relationships and regular social contact.

Mixed views were expressed with regards to therapy and medication (as will be discussed in more depth in chapter 6). Some participants viewed medication as likely to be useful, such as Sarah:

Sarah: well there's talking .. for example like counselling I think that's quite effective .. if you get the right counsellor for you, you've got to have .. I think there's got to be some sort of rapport there .. I think there's medication .. which I think I haven't taken it myself but ... I think ... well it must be pretty good otherwise they wouldn't keep doing it surely 'cause there's a lot of people on medication .. so that must have value

However most participants expressed a preference for not taking medication themselves; reasons for this were given as dependence (including psychological dependence), side effects and medication addressing the symptoms but not the cause of distress. There were more positive views in relation to counselling than to antidepressants, although it is perceived as an option that will not suit everyone. However, counselling was viewed as being potentially beneficial, with fewer side effects than medication (that is, side effects of counselling were not discussed, nor were any negative consequences, whereas negative aspects around medication were frequently mentioned). One participant (Sadie) expressed a wish to receive some form of therapy to help her overcome a bad relationship (the ending of which led to what she described as a period of depression, discussed earlier). She is scathing towards medication as it does not address the causes of emotional difficulties (in her example), whereas some form of therapy might help to change her *thinking* (this is not reflected in the excerpt but is drawn from earlier discussion):

Sue: you said about drugs that you didn't think medication like wasn't very useful um .. can you tell me a bit more about that

*Sadie: just for me I don't think it would um [...] I can't see a tablet helping me to be honest, not not with mental health..I can't see.. yeah if you're ill .. you know antibiotic or a paracetamol but I can't see how a tablet would make you feel better, if you was feeling depressed about something in your life only **you** can change that do you know what I mean, if you've got a bad relationship only I can change that by physically doing something to make it better .. I don't think taking a tablet would help I really don't [emphasis in participant's speech]*

Medication was perceived as particularly useful when participants viewed causation as biological, and used an 'illness' framework. An interesting example of this is Michelle, who had strong views against medical help for mental health problems, for a number of reasons including disagreement with treatment methods and a preferred 'holistic' approach (that is, one that examined the whole of a person's life such as lifestyle and relationships). She did, however, express that in the event of postnatal depression, she could be encouraged to seek help 'because I can see that as like a biochemical reason why I'd need help' (Michelle). In this instance, she views postnatal depression as being caused by chemical changes within the body, as opposed to lifestyle and social causes that she more closely associates with mental health problems.

Discussion

Prior *et al.* (2003) found that individuals perceive social causes to underlie mental health problems, and that emotional distress relates to 'problems of living'. Indeed, Schomerus *et al.*'s (2006) findings were that their lay public viewed depression as caused by psychosocial factors; the social has a strong relevance to lay understanding. Prior *et al.* (2003) argue that because emotional distress was viewed as a 'problem of living' by their respondents, it did not necessarily occur to the respondents to consult medical help as medical help was not perceived to be beneficial. They also found that individuals frequently held negative views around medication. Participants in this study provide some support for these assertions; medication is seen as not necessarily beneficial, especially when side effects are taken into account, as has also been expressed by Williams and Calnan (1996) in relation to lay views about *physical* illnesses. However, there is also *some* support for medical help in the face of mental health difficulties; those who held beliefs more closely related to biological causation were more likely to view medical help as appropriate. The importance of social support was also expressed, whether as the sole response to someone in distress, or as an adjunct to formal care. The importance of friendship was expressed in terms of helping to overcome distress, and also in terms of receiving practical help in relation to any distressing circumstances. However, it is important to refer back to a point made earlier on in this chapter, which is that distress and mental health problems are terms that were somewhat

interchangeable in participants' descriptions. What appears to be viewed as the causes of mental health problems – life problems – may also reflect what people are describing as a cause of misery, and so the idea that friendship and support are useful in helping to ameliorate such problems may reflect this.

Blaxter (1990) talks about the importance that is placed upon individual behaviour when considering susceptibility to specific health problems (in a survey relating to *physical* health problems), although when her respondents were asked to account for *their own* health problems, this was less the case (Blaxter 1990). Blaxter therefore suggests that causation in relation to poor physical health is viewed as somewhere between structural factors (including poverty) and individual blame, depending upon the type of illness being discussed and its proximity to the respondent's own life. It appears as though this is salient in relation to mental health, both in terms of causes, and also in relation to coping. Coping is seen as the difference between experiencing mental health problems or not (Pill and Stott 1982); some individuals are held as partly responsible for any failure to cope, and some respondents in the lay section point out their own successful coping mechanisms, evidencing their own 'claim' to good health (Radley and Billig 1996). Thus, when considering discussion around causation and also around individual attributes, it is important to remember that participants were discussing 'others' and that this might inherently affect the level on which blame is attributed. Even though useful insight is gained from understanding participant's views, these views may change depending upon the type of difficulty being discussed, and its proximity to their own lives. When considering causation, the example given by Nell – about a friend whose problems appeared to begin with the breakdown of a relationship – is an example of Bury's (1997) 'lay epidemiology'. Blaxter (1993) suggests that individuals 'reconstruct biomedical concepts, including those of aetiology, in the light of their own biographies' (Blaxter 1993, p.141), and I would expand this to include *other's* biographies. Sense is made of events according to the knowledge that individuals already held, and this in turn is influenced by events.

The importance given to receiving *practical* help – that is, help with the perceived causes of a person's distress – reflects the causation attributed to social factors, and that emotional distress is a 'problem of living'. Additionally

however, this also allows individuals to provide care and advice upon matters they feel familiar with, and that fall within the remit of their capabilities.

The relationship between lay understanding and hypothetical help-seeking: 'consistency'

This section discusses how the analysis of the data, in relation to lay understanding and help-seeking, has elucidated the relationship between the two amongst the lay group; there were no direct questions relating to this relationship, as such a question was considered rather complex to ask, and would involve discussing the underlying rationale behind the study (which might then affect an individual's response). However, it was possible to trace a discernible 'logic' within each participant's discussion that showed their preferred help-seeking choices, alongside their corresponding rationale.

Two participants whose understanding showed a clear relationship with their hypothetical help-seeking were Phil and Michelle, whose views were also both against the use of GPs. Phil is a Buddhist, and the excerpt of his speech in the first section of this chapter shows that in the event of distress, the most appropriate action *for himself* would be found within his religion. Phil relates stress (which he views as synonymous with 'distress') to 'modern living' and the pace at which life is conducted in the present day. He contrasts this with time he has spent in a monastery, and the sense of peace that descended over him during his stay there. He regularly meditates and finds this a useful way to remain calm and relaxed in his everyday life; for Phil, therefore, a source of help would lie in his religion. Michelle has a different view of mental health problems and suggests, drawing from her degree in psychology, that problems arise from allowing destructive thought patterns to emerge and continue. She also suggests that lifestyle plays a big role in helping the emotions to be well-regulated, and that in the event of distress a person would need to take stock of their life and assess what aspects are causing their problems. She holds very individualising views around where blame lies in the development of mental health problems. She speculates that in the event of distress, she would hope to assess what was causing her difficulties in her life, and address the cause; specifically, she would not consult a GP, and to do so would represent 'failure' on her part to adequately manage her own life. These two examples provide the

clearest links between underlying belief systems and hypothesised help-seeking that simultaneously suggest pathways that do not lead to a GP.

Amongst other participants, there was frequent referral to GP help as being potentially useful, and where participants viewed the causes of mental health problems as biological (or for example, a specific diagnosis of schizophrenia was discussed), this was particularly the case. The most commonly-perceived cause of mental health problems was in relation to social factors; friends and family were frequently cited as being sources of support and help, though this may be in conjunction with visiting a GP, and/or receiving counselling. It is important to point out that views were not necessarily consistent in terms of drawing from one particular paradigm or another, as discussed in the first section of this chapter; participants drew from more than one paradigm, and views may have contained 'contradiction' if examined from a particular theoretical perspective.

Discussion

The above sections provide some insight into how participants view the development of mental health problems and how best to help them. The most striking common thread is that participants view mental health problems as being caused by social problems, and also significantly helped through social contact. Whilst social causes do not account for the entirety of understanding expressed in this area, it accounts for a significant part of understanding and it is therefore highly pertinent to consider the implications this might have for treatment seeking. As discussed in the literature review, some of the literature around help-seeking indicates that beliefs around mental health may map onto treatment models (Angermeyer *et al.* 1999, Angermeyer and Matschinger 1999) and Sayce (2000) suggests that what individuals perceive to be the cause of mental health problems is likely to impact upon what they perceive to ameliorate or cure them. There is *some* evidence of this in the data, as just discussed. Indeed, when comparing the most commonly-cited causative and healing factors, it would be tempting to conclude that the most commonly perceived cause is related to the most commonly perceived curative factor; that is, problems arising from the social can lead to mental health problems, and also that meaningful social support from others can help such problems to be

overcome. However it is important to steer clear of any reliance on a consistent relationship between perceived causality and perceived cure. It is important to bear in mind the nature of understanding around mental health; that understanding is idiosyncratic, biographical, philosophical and fluid. Views may draw from more than one paradigm simultaneously, and thus views around causation do not necessarily map onto views around appropriate treatment when viewed from a particular theoretical perspective, even though they do sometimes map onto each other. It is important therefore to acknowledge that within a person's own understanding, there is consistency, but not necessarily a consistency that might be acknowledged from a particular theoretical perspective. Bury's (1997) assertion mentioned in the first section of this chapter, relating to caution about inferring action based upon lay understanding, remains pertinent. Whilst some theorists suggest that understanding around mental health impacts upon treatment seeking, the implicit expectation that there is a logic linking understanding and action may be related to the theorist's own perspective rather than necessarily reflecting a relationship between understanding and action.

There is also another important caveat to mention regarding the relationship between lay understanding and hypothetical help-seeking; that is, specifically, the fact that it is *hypothetical*. Whilst it is possible to ask someone to speculate on their behaviour in a certain situation, this does not necessarily mean they will act as such in that situation. Indeed, when considering lay understanding and hypothetical help-seeking, it is likely that respondents would draw upon their own theories about the nature of problems and appropriate help; the process of hypothesising, of necessity, draws upon a particular theoretical perspective. Thus, a link between hypothetical help-seeking and lay understanding is likely to be observed, but this does not necessarily bear resemblance to the reality of help-seeking. It is to that 'reality' that the next chapter will turn.

In relation to specific examples of lay understanding mapping on to hypothetical action, Michelle's example provides interesting confirmation of recent research; her stigmatising views around the blame attributed to individuals, and her preference for eschewing medical help, chime with recent research by Griffiths *et al.* (2011) that individuals who hold stigmatising

beliefs are likely to prefer self-care in the event of depression. In addition, Phil's preference for seeking help from a Buddhist monk is a useful illustration of Pescosolido and Boyer's (1999) assertion made in the literature review (I am providing an abridged version here):

If individuals see mental health problems as crises of faith, as bad marriages, or as any of a number of other things besides illness, they may consult faith healers, spiritualists, the clergy, or other people (Pescosolido and Boyer 1999, p.408)

Whilst there are demonstrable links between lay understanding and hypothetical help-seeking in most cases, it is important to then contrast this against actual help-seeking, as will be done in the next chapter.

Conclusion: the applications and limitations of lay understanding in elucidating help-seeking behaviour

Research into the content and nature of lay understanding is useful in elucidating the context in which help-seeking decisions are made; it highlights the different knowledge that individuals might call upon in the event of distress, as well as Freidson's (1970) 'lay referral networks' that form the context in which help and advice might be given. However, it is important to bear in mind that lay understanding may be limited in its capacity to predict what individuals might actually do in the event of distress, as it is based upon a hypothetical scenario. As mentioned in the literature review, Blaxter (2010) and Bury (1997) both caution against assuming that behaviour can be inferred based upon knowledge of someone's beliefs. It is therefore necessary to consider where benefit lies in increased understanding of lay knowledge.

Firstly, it is useful to understand more about the mechanisms by which people *identify* and *label* a person's experience as falling within the remit of 'mental health'; in a contemporary context, little is known about this within the UK, and this study therefore provides useful and original insight into the nuances of this process, alongside potential reasons for delay. This represents one area of originality in this study. The continuing salience of Zola's (1973) triggers has also been discussed, and the difficulties in defining when a

person's inner experience is a 'problem' or not are discussed, outlining the relevance of a breakdown in ability to cope or to meet daily obligations, and the importance of physical cues.

Secondly, this study provides greater understanding of the ways in which support and practical help might be given. There is an emphasis on addressing problems that *underlie* distress, as opposed to dealing with distress as an entity in itself; this addresses the 'cause' as well as falling within the remit of problems that participants feel able to address, or talk about, with some confidence (such as relationships, financial problems, bereavement). Great emphasis is placed upon the role of the social; this was already known to a significant extent within the literature, although it is useful to confirm that this remains the case, and in conjunction with beliefs around the nature of social support in ameliorating mental health problems. The context in which help-seeking decisions are made is therefore significantly geared towards viewing distress that arises from life problems as falling within the remit of mental health, although paradoxically (when viewed from a perspective that views mental health as a paradigm pertaining to psychiatry and/or psychology, and associated 'treatment'), a medical/therapeutic response may not be desired or viewed as beneficial. Whilst terms such as 'mental health problems' are used to articulate distress, it must not be assumed that this implies a desire for a medical or a psychological solution. Professionalised terms may be used in lay understanding, but this does not mean that an appropriate paradigm is also employed as a solution. Whilst this may mean medicalisation may be taking place within contemporary understanding, there are limits to the extent of this medicalisation.

It is pertinent to reiterate that *this* chapter does outline a link between what individuals perceive to be the causes of mental health problems, and how they might seek help. However, whilst lay understanding is internally coherent, this need not necessarily reflect paradigmatic consistency. In addition, the lay understanding discussed related to hypothetical scenarios. The next chapter will consider whether lay understanding plays a role in help-seeking, using the stories of recent help-seekers.

Chapter 5

Understanding help-seeking from the perspective of help-seekers: from ‘a matter of interpretation’ to contextually determined outcomes

This chapter focuses on the stories of help-seekers, and in particular on the process of interpretation of distress that culminated in attending a GP consultation. Recent interpretivist research suggests that the meanings attributed to illness are central to the help-seeking process (Biddle *et al.* 2007) and so it was an aim of this research to try and access how individuals interpreted their distress, including how they came to classify it as amenable to help from a GP. The data suggest that the interpretation of distress is particularly challenging for individuals who are experiencing extreme and ongoing distressing circumstances, and their distress may not actually be interpreted as anything that is amenable to help. Whilst the process of normalisation has long been understood (Biddle *et al.* 2007, Clausen and Yarrow 1955, Mechanic 1968), two participants’ stories provide insight into how their distress was particularly amenable to normalisation, and explain their non-help-seeking (or delayed help-seeking) in these terms. Their stories also shed light on the importance of networks around an individual, and the remainder of this chapter examines how individuals’ networks played a role in their story.

By viewing the people around an individual as playing a role, help-seeking stories are more clearly understood, and the research points towards the importance of understanding help-seeking as a process that is context-bound, and not wholly individualistic. The data supports a shift from more individualised notions of help-seeking (that frequently underlie research that examines unitary factors such as gender and need) towards conceptualising help-seeking as context-bound and shaped by a person’s wider network, as per current work by Pescosolido (2011). Additionally, help-seekers’ stories help to illuminate the limitations of lay knowledge in affecting help-seeking. Whilst lay knowledge might help individuals to recognise a person’s experience as a ‘mental health problem’, their actual seeking of help is likely to be affected by other factors including the life events and resources surrounding the individual.

It is stated in Mechanic and Volkart's (1961) definition of illness behaviour given in the literature review, that a key underlying factor in illness behaviour (and therefore in the help-seeking process) is the recognition of some kind of *problem*, and its classification as potentially amenable to care within a medical context. The data suggest that there are specific challenges in the recognition of *a problem* for people who are experiencing significantly distressing ongoing circumstances, and for whom extreme distress is to be expected. This chapter will consider these two factors (the identification of a problem, and its classification as amenable to medical help), using the stories of help-seekers to elucidate different ways in which their distress came to be presented within a primary care setting. I will discuss the difficulties (and facilitators) of identification of distress as something that can be viewed as a 'mental health problem', and how a person's context has a significant impact upon this, including the specific resources to which they might have access.

A matter of interpretation: difficulties ascertaining what is 'wrong'

In all the interviews held with help-seekers, participants' stories of distress revolve around distressing circumstances that are either ongoing in their lives (for most of the recent help-seekers), or caused significant distress in the past that remains with them in the present (this applied to the longer-term help-seekers plus one recent help-seeker). Participants' distress is inseparable from the 'life problems' that caused it, in terms of how it is presented and also *understood*. For two participants in particular, this caused significant difficulty in the process of actually recognising there was something 'wrong', other than what was causing their distress to begin with; this was an important factor in non-help-seeking for these two participants who were experiencing extremely distressing circumstances. I will now illustrate this with reference to their stories. This insight first came about as a result of 'difficult' moments during interviews where there was clearly an assumption on the part of the interviewer that did not bear reality to the experience of the participant, an example of what May (2002) discusses as revealing the extent to which research assumptions have guided the interview schedule. Holstein and Gubrium (1995) point to the importance of paying attention to such moments as they hold great potential for insight. Participants were asked to describe their pathways towards seeking

help, and this line of questioning involved asking about what (if anything) might have been tried before consulting a GP. This question elicited some unexpected yet ‘obvious’ (to the participants) responses that in order to seek help an individual needs to be aware of and recognise some kind of *problem*, and I will illustrate this with reference to their stories.

Two participants each pointed out that they didn’t realise anything was wrong, and that seeking help via a GP or in any other way was therefore not something that occurred to them. In each example, they only sought help when their problems had become rather serious, and other people intervened. Dylan’s story, as a new help-seeker, is one of distress arising from and/or accompanying multiple distressing circumstances that showed little sign of abating. He had been experiencing health problems for a period of four or five years, during which his health had impacted on his ability to work and he became unemployed; this was then followed by subsequent housing problems. He went on to describe a period of time over which friends and family were telling him that something was wrong, and that it was only after a period of reflection and standing back to examine his behaviour and feelings that he realised something had changed. By this time he had let go of his relationship, avoided social activities and was experiencing significant mood swings that meant he preferred to be alone. Even at that point, he still did not view his inner feelings as ‘wrong’ in any way, he was simply dealing with multiple stressing factors and assumed that his distress was just something he had to endure, as he was still experiencing his difficult circumstances; his circumstances were sufficient explanation for any distress:

Dylan: I just thought personally, it was just taking all the medication and tablets and stuff that that was like putting me down ... I just blamed it on that you know my medication .. and it weren’t you know what I mean

For Dylan, even though he describes his inner feelings becoming more and more desperate, it wasn’t until he was told by a specialist – relating to his physical health problems – that he should visit his GP in relation to his mental health, that he did something about it. He didn’t realise there was anything wrong, and certainly not related to his mental health, as he knew ‘nothing

about it' [the topic of mental health and what it encompassed]. His consultant played a key role in noticing a change in him, bringing it to his attention and providing signposting advice to visit his GP. At this point, the efforts of his family at helping him to notice a change in himself, along with his very difficult inner feelings, meant that he was more receptive to viewing his inner feelings as 'problematic'. Dylan stated that he knew nothing about the topic of mental health, and it is worth considering that a lack of understanding in this area contributed to him not interpreting his experience using such a framework. However, his extremely distressing circumstances also played a role in rendering any objective concept of 'normal' as something that would inevitably involve being distressed. He describes a gradual wearing down of his energies, through the constant and ongoing difficult circumstances he was trying to endure; though he was enduring difficult circumstances, he hadn't yet reached a point of 'crisis':

Sue: so you didn't seek help earlier partly because you just thought .. it was a stage of life, maybe, [hear: 'yeah'] something that's just, you know, you've gotta get through²

Dylan: yeah and then it's just ... it's like being in a swimming pool where you can't get out... it's like you're always swimming and you're dying to get out .. you just can't .. not like drowning or owt [anything] it's just being stuck in the deep end the whole time

Dylan's metaphor of his experience describes him as being permanently 'in the deep end', having to continually strive to stay afloat and gradually becoming more and more tired, but remaining in these difficult circumstances and remaining 'afloat'. It took years for Dylan to realise there was something 'wrong', and a significant factor in this was the presence of sufficiently difficult circumstances to explain his distress – it was particularly amenable to being normalised.

² It should be noted here that the my own speech in this excerpt is summarising what Dylan had already said, and does not involve introducing new ideas

Tanya describes a set of very difficult circumstances during which she wasn't aware that feeling low, and having no self confidence, wasn't 'normal'. She describes a point in her life when she took an overdose, the trigger for her coming into contact with mental health services. Her childhood had been blighted by sexual abuse, and her overdose came following the breakdown of her marriage that had been blighted by domestic violence. At the time, she was living with her mother, with whom she had a difficult relationship and who wasn't speaking to Tanya. She described having no one in particular to talk to at the time; she did not have a supportive family and wasn't really aware of doctors being potentially helpful in relation to mental health, at that time. When asked about why she didn't seek help, she explained that she didn't know there was anything wrong with her – she was unaware how she was *supposed* to feel – and questions how she was supposed to know that anything was 'wrong' with her feelings:

Sue: up until that point, had you thought of um .. doctor's involvement was there anything .. or had it not crossed your mind

Tanya: Um ... When I go way way back, I don't think I realised how ..extensive my problems were ... I think everything was all .. internalised ... and I thought that was probably the normal way to be, to feel that way and to not have any confidence and that you know, it was only ... certain situations that sparked off me seeing people, [her first contact with services] you know .. it had to escalate to something severe happening, you know how do we know when there's something wrong with us if nobody tells us .. you know

Tanya was in a very distressing situation where the presence of extreme distress was to be expected. In addition, she knew little about the subject of mental health, and this is likely to have compounded her inability to recognise that something was indeed wrong. For Tanya, the lack of people supporting her (and in particular, providing sanctioning to seek help and/or identify that help might be beneficial) is likely to have compounded the fact that she didn't recognise a 'problem' other than her incredibly distressing circumstances. No help was sought until she tried to take her own life and help was sought for her.

Tanya's early experience of seeking help (or, more appropriately, having help sought on her behalf) bore strong similarity to Dylan's in how she didn't think that there was anything unusual in her extreme levels of distress. Whilst Tanya's current help-seeking patterns are now very different, her early experience sheds light on the process of first coming into care, as with Dylan's recent experience.

Identification of a 'problem' is therefore essential for help-seeking to take place. For participants experiencing multiple or ongoing difficulties, and for whom distress is to be expected, the labelling of their distress as anything but 'their problems' is unnatural. The coexistence of severely distressing circumstances (and in particular, circumstances that are not temporary or sudden, but rather ongoing and a part of their wider life) at once increases the levels of distress in their lives and also renders it likely that their distress will be viewed as 'a part of life' as opposed to something that could necessarily be helped by any form of intervention. David's story, briefly discussed in chapter 3 in the section on ethics, also followed a similar pattern; he had no idea that there was something 'wrong' with his emotions, he was just extremely distressed because he had to face the possibility that he might die from cancer. The idea that he was also depressed came as a shock to him, and he had not been aware that anything might be 'wrong' with him until a nurse told him to seek help. In addition to their distressing circumstances, Dylan and Tanya both point out that they had little understanding around the topic of mental health (or of services that might be geared towards people experiencing distress) and this is likely to have rendered any identification of a 'problem' with their inner feelings (that is, interpreting them as signifying some kind of mental health problem) particularly difficult. Low mental health literacy does appear to be pertinent as well as the experience of extremely distressing circumstances. For problems to be labelled as relating specifically to 'mental health', participants were therefore partly reliant on others around them doing the labelling.

Discussion

The concept of normalisation is frequently discussed as a factor in the delay of help-seeking; the examples given above provide useful illustrations of how the experience of extremely distressing circumstances lends itself to

normalisation. Any notion of what ‘normal’ *should* feel like was particularly hard to conceptualise; it was particularly hard for certain individuals to identify whether anything was in fact ‘wrong’ other than their distressing circumstances. It is pertinent to reiterate that individuals were unable to know that their inner experiences *should* be any different; they had no way of knowing what a ‘normal’ response would have been in their situation (both of these measures being socially defined), and it was the intervention of others that finally brought them into care. What is notable about these participants’ stories is that the close alliance between the life problems and distress renders categorisation of something ‘wrong’ a difficult process, potentially obscuring the need to seek help until a person’s wider network intervenes.

There are two related debates that this could also feed into, that I will only signpost here: the first is that it could be argued that this provides support for a perspective of social causation, that is, that the experience of distressing life circumstances renders the development of mental health problems more likely. It is not possible to further address this argument within the remit of this study. Alternatively, given their very distressing circumstances, the idea that there was a ‘disorder’ present, *i.e.* that their response was in some way pathological, could be viewed as inappropriate. This discussion, which feeds into ideas summarised by Pilgrim and Bentall (1999) about the disutility of viewing distress that is socially derived as an ‘illness’, is also too large to be discussed here.

I will now discuss the role of others (referred to as ‘wider networks’) in helping individuals come into care.

The role of an individual’s wider network in the help-seeking process

This section will consider how participants’ help-seeking trajectories were affected by their social context (or not). I will consider how certain participants’ stories involve other people, and how these other people shaped the specific trajectories taken. It should be noted that, as the participants in this study comprise a heterogeneous group of help-seekers, there are some whose help-seeking did not involve other people. This section will show how the data supports an approach that views help-seeking as contextually-shaped; whilst *some* individuals did not discuss other people as playing a role in their story

(whether in relation to their distress, access to resources or sanctioning), the role of other people is significant in other stories. I will also consider whether there are meaningful differences between those who received help from others, and those who did not. This section contains a number of sub-themes and so has been divided into discrete sections in order to facilitate clarity of data presentation and analysis; data will be presented and analysed, with corresponding discussion following each sub-theme in turn. I will then provide a brief discussion summarising the section as a unified whole.

When referring to ‘social context’, I am referring to the people around the individual – their wider network; this includes people with whom the individual has meaningful contact: friends, family, colleagues and their wider community (such as people who work in an advisory capacity, including GPs). This could be likened to social networks, and to social capital, both of which are viewed as ways of shaping pathways to care, as discussed in the literature review. I will go on to highlight one specific aspect of the network – regular contact with healthcare professionals – as particularly salient. I will use the terms ‘context’ and ‘network’ interchangeably for this discussion.

Identifying a ‘problem’

As identified above in Dylan’s example, the people around him played an important role in noticing changes in him, identifying that there might be a problem (above and beyond his difficult living circumstances), and helping him come into contact with some form of care. His help seeking cannot be viewed as an individual process but one that was very much a product of his context, that is, it includes the intervention of the people around him. I will now address how and when help-seekers’ contexts may have played a role in them coming into care, drawing further upon the examples mentioned above, as well as the other help-seeking participants.

Returning back to Dylan initially, his is the clearest example of a person’s network helping them come into care. Dylan had no awareness of any change in himself, and it was only after many comments from his friends and family, telling him that he had changed and that there was something actually wrong with him, that he began to see it himself:

Dylan: over the last four years, five years you could say, my social life my mates and friends, people have seen changes in me .. I mean I don't notice them .. they been saying 'you're not the same as what you was, you don't .. look normal you don't act normal ...you're not the same' ... I just thought it was just ... being normal you know what I mean and it's just .. accumulated and thing's just .. kept building up and building up and building up and building up and it's got to the stage that ... where it just got to the point where I thought 'bloody hell, there is something wrong' ... it took me four years, nearly five years to realise ... that there is .. there was something drastically wrong [...] and I could see in my'sen [myself] that I'd changed ... and I don't know why that was but it just .. something just clicked one day .. and then my parents were worried about me, my brothers, it's just got to the stage where they said you need to do something Dylan, you know when someone's always trying to push you to do something..I thought 'oh I could deal with it my'sen' [myself] .. it got a point where I couldn't

Dylan's actual help-seeking took place when a hospital consultant noticed a drastic change in him, and advised him to seek help from his GP; it was this additional push that finally led Dylan to seek help. His network played an important role in helping him to realise that there was a problem and in directing him towards appropriate help. The advice of a healthcare professional played an important role in this.

Anna has been in contact with mental health services for roughly eighteen years; she is one of the long-term help-seekers interviewed. Her recent help-seeking involved sanctioning from her partner, upon intensification of suicidal feelings that were causing them both concern. Her recent help-seeking is therefore the outcome of her own interpretation plus the support and concern of her partner; this differs somewhat from her history of seeking help. She talks about a history of mental health problems that she attempted to deal with on her own; prior to coming into contact with care, she was aware that there was something wrong but she wished to keep her problems to herself because she believed that it was important to deal with problems without outside help:

Sue: you've said that you've had mental health problems since childhood [hear: 'yes'] but that you coped with them up until the accident

Anna: um... I tried to cope with it I'm not saying I did very well at coping with them um [...] I kind of come from a background where it was drilled into me that your problems are your problems you don't share them with other people, you don't show to other people you deal with them so .. I'd kind of been brought up feeling that I couldn't ask for help .. and that I just had to somehow make it through, that that was my problem and I had to deal with it so until I really did fall apart, completely fall apart um .. I was .. I was coping, badly but I was coping ..

Anna had a very strong desire to keep her problems to herself and deal with them in her own way, which she had been able to do until she was involved in a serious accident in which she sustained permanent physical injuries. It was while she was in hospital (she had to stay in hospital for 'some time' after her accident) that a consultant observed her mental health difficulties and she was referred to a psychiatrist.

Sue: could you tell me a little bit about how you found help at that [first] time ..

Anna: um that was.. again a referral it came through the hospital at that time and because as a result of the accident I spent some time in hospital um, and one of the consultants was aware that my mental health state wasn't good [...] so the consultant contacted the psychiatric department um and .. I was referred to a psychiatrist that way um .. and initially he came to see me on the ward while I was still in and then um I had a number of appointments with him and again once I was discharged ..

She therefore came into care (relating to her mental health) as a result of already being in a medical setting; her distress was observed and categorised as a mental health difficulty that was amenable to help, and it was by being in contact with medical professionals over a period of time that this process of observation and categorisation was enabled. She describes a period a few years later when she was experiencing significant problems again:

Anna: I actually moved out of the area [from one city to another] um and that kind of ended that particular period of psychiatric help because um .. I didn't feel well enough at that time to seek help again for myself in my new area, um and it wasn't until I had a suicide attempt and was taken into hospital that I was referred back into psychiatric services again in the new area ..

At this point, Anna describes being too unwell to seek help for herself, and help was only sought on her behalf following a suicide attempt. Anna doesn't describe having any support in this new area, although she does not mention any friends or family and so it may simply be that in this respect her network's role remained unsaid. However, this episode stands in contrast to her most recent contact with her GP, when she sought help on the advice (and with the support) of her partner, upon the intensification of her suicidal feelings. Anna's story provides different examples of when she did and did not seek help, in different contexts. Her presence in medical care played a pivotal role in her accessing help (indeed, she would have preferred to keep her problems to herself). She later seeks help upon the advice of her partner, and this is in contrast to a previous episode when she felt too unwell to seek help, at which point she was not involved with her current partner and does not refer to receiving support from anyone else. Anna's help-seeking has therefore been significantly affected by support and/or intervention from other people.

Kara's experience shows some evidence of support from others, though it is unclear as to the extent that they played a role; she describes being repeatedly encouraged by her friend to seek care. Kara, who grew up in a home blighted by domestic violence that she left a few years previously, initially sought help for sleep problems. While she was at her GP consultation she broke down and said that she couldn't cope with her inner feelings. She describes that this was not premeditated, although she does point out that her friend had been encouraging her to do so:

Kara: my friend that I've just been on about [a friend she had previously been talking about to illustrate a story of depression] she tried pushing me for [laughs] she's been trying to push me for the last two or three

years since I've known her probably .. um to go and speak to someone .. she says 'you probably don't need antidepressants you probably just need to go and have a chat'

Kara's story will be discussed in more detail in chapter 6, suffice to say that she did not specifically think she had a problem, although she periodically engaged in risky behaviours that affected her relationships with her partner and with her friends. Kara's story contains some contradiction; she talks about not thinking she had a problem, though she later says that she felt that on some level she *knew* she had a problem and that she'd been concerned about the consequences of seeking help and of having her daughter taken away from her. This contradiction must be borne in mind. However, she does speak of her friend encouraging her to seek help, and this may have played a role in her decision to speak to her GP when her feelings became overwhelming. In Kara's example, it was her difficulty sleeping (a *physical* cue) that led her to seek help from her GP, and once in the consultation she expressed her difficult feelings. It is difficult to know the extent that 'sanctioning' by others played a role; indeed, in Dylan's example too, it is possible to see that sanctioning was ongoing, even though help was only sought when a hospital consultant advised him to do so. In these examples, sanctioning may have been tempered by denial or a belief that their problems are not severe (discussed as barriers in the literature review) and concern over the consequences of seeking help (such as Kara's expressed concern about her child being taken away). Kara's example does not clearly demonstrate the *impact* of her network, although it does provide an example that there was some attempt at helping her towards seeking formal help (and in this case, by someone who had experience of care relating to mental health). As this section is addressing the role of networks, it is important to consider those whose stories do and do not support the theme, so that negative cases can potentially enhance understanding.

Tanya's experience, as mentioned above, was one where she did not come into care until help was sought for her after a suicide attempt. Her network did not help her identify any problems, and indeed she was living in very difficult circumstances after leaving her marriage that was blighted by domestic violence. Tanya describes a period of living with her mother, when

they were not on speaking terms; during this time she suspects that she had a breakdown (she applies this label after the event) although at the time, she did not know what was wrong. She describes:

Tanya: my body just went into like um ... like jelly .. I just .. was like a walking zombie .. and there was ..situations surrounding it at the time which was my ex-husband, and my mum wouldn't speak to me and I was living back with my mum and there was just no support around me and I just remember waking up one day and feeling something's happened to me, I just don't feel like I'm functioning on a normal level um .. but it's only probably a year or so after that I looked back and thought 'that was a nervous breakdown' but I wasn't aware of what it was at the time I had no one to speak to, I wasn't very aware of doctors and therapy I didn't have a supportive family, you know ..

As mentioned above, help was sought for Tanya following a suicide attempt. Her network did not help her to identify her problems or to enter care, nor did it play a supportive role (indeed her home life may have contributed to her distress), and it provides an example of how a network might *fail* to support an individual.

The remaining help-seeking participants do not mention their networks in terms of coming into care, although Debbie's story does not fit into either group because her original help-seeking took place when she was a child, at which point it is expected that help would be sought for her, as opposed to her seeking it independently. Debbie is a long-term help-seeker and her initial help-seeking took place when she was seven years old. Her current help-seeking patterns reflect her own decisions to seek help; when experiencing a period of distress, she engages in self-management including 'watchful waiting' (Cape *et al.* 2000) and only consults her GP if she feels that her problems are not improving.

Cath sought help from her GP when her attempts to deal with the cause of her distress (the ill-treatment of her by her employer) failed. She attempted to resolve her problems with her employer, but when the ill-treatment continued and she found herself unable to attend work without experiencing

extreme anxiety, she consulted her GP who recommended a month away from work. In this instance, her network did not help resolve her problems, although her network – in particular, her employer – was in some way responsible for her distress. She was unable to resolve her problems by repairing their working relationship, and so she resorted to dealing with the associated distress itself. Upon finding new employment soon after returning to work, her problems were resolved. In this example, she attends a consultation when she feels that more practical alternatives have been exhausted; she does not need help identifying that there is a problem. Her GP is sympathetic towards her problems and diagnoses ‘work-related stress’.

Antonio’s example provides no reference to his network in this instance. His seeking of care was for the purpose of finding out whether his physical health was in any way threatened by his inability to relax, following the death of his mother. He was struggling to deal with his grief, and since his mother’s death had been suffering from headaches, and seemed unable to relax as he previously could. He was concerned that his health might suffer, whether temporarily or permanently, at a time when his health needed to be particularly good; his wife was pregnant with his second child and he was concerned that he remain fit enough to work and be involved in parenting. Antonio therefore recognised some form of problem, and sought advice as to the potential consequences of this problem; he also hoped to receive some advice on how to deal with his grief, and how to relax more effectively.

Patrick’s help-seeking took place as a result of a panic attack, related to his health fears. Patrick had recently been told that he was at high risk of a stroke or heart attack, and recently witnessed the death of an old friend who was diagnosed with the same condition (atrial fibrillation). The symptoms of his panic attack (raised blood pressure and raised heartbeat) are similar to those of his condition worsening to a heart attack, and this increases his panic; his seeking of help was therefore for emergency assistance from his GP, who placed him on a heart monitor and assessed his condition. Had his GP not been available he would have called for an ambulance. His seeking of help is specifically health-related; Patrick was very aware that there was some form of problem, but he feared that it may be his physical health as opposed to a panic

attack. He did not require help in identifying a problem, or in selecting a course of action.

Sally Anne's story does not provide an overt use of networks. She is frequently within a medical setting because she is undergoing investigations for age-related physical changes; she sought help initially following a 'fracas' that left her very distressed, and she was prescribed Valium by her GP. It is not clear whether she attended this initial appointment specifically because of this fracas, or whether she was at a GP consultation relating to her physical health, and also spoke about her experience. At a subsequent appointment with a different GP (in relation to her physical health problems) she requested additional Valium and was told that she was not allowed; she was prescribed antidepressants and referred to counselling. Her presence in a medical setting enabled her request for additional medication (and her previous experience also framed her expectation of Valium). Whilst it is not clear whether she initially sought help only because of her distress, or whether she was already present in a medical setting and so decided to discuss it, it *is* clear that she was able to discern that there was something wrong *i.e.* that she was very distressed, and that a GP might be able to provide her with help.

Specifically, for those participants who did not refer to their networks as playing a role (Cath, Antonio, Patrick and Sally Anne), they were able to identify some kind of problem and also choose their GP as a potential source of help. For those whose networks were mentioned (Dylan, Anna and Kara, and also David's story given in chapter 3), the process of identifying a problem took longer and was more complex; their networks ultimately helped them to identify that something was wrong, or at least provided some confirmation (or 'sanctioning') that there was a problem and that help might be suitable. For Tanya, who was unaware that there was a problem, her network appears to have failed in helping her realise there was a problem, and no help was sought for her until she attempted to take her own life. The role of networks therefore appears to be most relevant where individuals are unaware that there is a problem, or are struggling to interpret their experiences. This may seem to be a truism, in that only those who were unable to help themselves (or were not doing so) were likely to trigger others into advising some form of help; however, it remains pertinent to point this out, as problems of interpretation

have already been highlighted above as a potential significant barrier to the seeking of help.

Discussion

This section provides an illustration of the importance of other people in helping certain individuals come into care. It leads on from the previous section that showed how certain individuals were particularly unable to recognise a problem within themselves, and thus relied on help from others. It is salient to note that for those individuals whose accounts do not include reference to other people, there was a more clear recognition of distress within themselves, and thus their distress was dealt with more swiftly. The help of others therefore plays a role in helping individuals to recognise that a problem exists (or rather, categorise their problems as within the realm of ‘mental health’). This feeds into current research by Pescosolido (2011), whose recent work supports a similar argument – that a person’s wider network plays a significant role in their access to formal resources. For those whose network helped to bring them into care, Zola’s (1973) ‘triggers’ remain pertinent, in that ‘sanctioning’ played a role; in addition, whilst ‘interference with social functioning’ has already been discussed as appearing in the lay group as a trigger, an additional trigger of Zola’s not yet mentioned in the findings – ‘the occurrence of a crisis’ – is pivotal for some of the help-seekers as a more immediate reason for seeking help. It is only when there is a sense of ‘emergency’ that a problem becomes clear. Therefore, in the examples of Sally Anne and Patrick in particular, their immediate need for relief led to their seeking of help.

Kara and Cath both show that once in a GP consultation, they both felt overwhelmed emotionally and expressed their inability to cope with their distress. The occurrence of some sort of crisis is therefore an additional trigger drawn from the work of Zola (1973) that is found in these stories, along with the salience of being able to cope with daily obligations, and the importance of physical cues that were discussed in the lay group. Blaxter (2010) discusses the salience of physical health to men’s help-seeking in particular, arising from the importance of being able to function normally, and Antonio’s help-seeking is

an example of such motivation; however, Patrick's help-seeking does not fit such a pattern as his health concerns were much more extreme and urgent.

As argued in the literature review (and as put forward by Pescosolido and Boyer (1999)), models that account for help-seeking have begun to cohere towards an acceptance that help-seeking outcomes are a product of a person's context, as well as of their individual predisposing characteristics. Thus, there is increasing acceptance of the importance of context in shaping whether (and how) individuals come into care. The Network Episode Model (NEM), which has continued to be revised over the last decade or so (Pescosolido *et al.* 1998, Pescosolido and Boyer 1999, Pescosolido 2011), has expanded to encompass an individual's context in a number of ways, as well as an individual's biology. The NEM seeks to explain more than help-seeking (it also addresses compliance with treatment, and an individual's *illness career*), but it also usefully locates help-seeking as being inherently contextual, and the data from this study supports such an approach. Rather than considering help-seeking as an individualised act (such as the focus of Biddle *et al.*'s (2007) Cycle of Avoidance (COA)), help-seeking must be viewed as an outcome of an individual alongside their context. The data in this section seeks to demonstrate that for individuals who were able to recognise a problem (and categorise it as potentially amenable to medical help), help-seeking was relatively clear-cut. However, for those who struggled to recognise that there was a problem (and in particular, those who were experiencing extremely distressing circumstances under which the experience of extreme distress was to be expected), their networks played a more important role. It is therefore not possible to account for help-seeking using a 'one size fits all' approach, but it is necessary to recognise that wider networks play a role for certain people. Whilst Biddle *et al.*'s work does provide valuable insight into the *internal* process that might take place, it is important to view this as an adjunct to an approach that also considers an individual's context. Pescosolido's (2011) continuing emphasis upon the role of networks and 'others' in the help-seeking process, which is embodied by the latest revision of the NEM – the NEM Phase III (2011) – is supported by the data in this study; this represents a useful qualitative UK-based adjunct to the work of Pescosolido, and represents an original finding from this perspective (that is, an in-depth qualitative, interpretivist study within

the UK). Freidson (1970) suggested that the influence of lay referral networks upon an individual's trajectory rendered help-seeking less an individualised act, and more an act that was the outcome of that person's network (*i.e.* the advice of others, in relation to the individual's problem). The salience of Freidson's argument remains, and may potentially be applied to other aspects of an individual's life, as I will discuss below.

It should also be noted, that in addition to networks helping individuals to recognise a problem, networks also appeared to play a role in the individual's distressing experiences. Pescosolido (2011, 2010) points out that the latest embodiment of the Network Episode Model – NEM III – usefully includes a person's context as a factor in the *causation* of their distress, as well as in *coming into care*. She argues that context is inseparable from a person's experience, and thus she argues for such a contextual approach. Whilst I have already stated that a discussion of causation is beyond the remit of this study, the study does point towards the intimate role that individuals' contexts have played in their stories, not just in them coming into care.

The rest of this section will be used to illustrate examples of how *specific* networks culminated in access to resources, including resources that may not have been available to all.

The role of networks in shaping access to resources: inclusion of stories from lay participants

It is interesting to introduce three participants' stories from the lay group, in order to further illustrate the role that networks can play in bringing a person's distress into care (or not). These stories provide insight into how members of the lay group have gone about seeking help based upon the resources they have available to them – resources that appear less available to the members in the help-seeking category. The examples that follow show how individuals were able to access help that reduced their need to seek care from a GP (or in one case, it shows how additional advice was sought *prior* to seeking help from a GP). These participants were able to access resources that are not universally available, by deed of their status as employed, student and high socio-economic status respectively.

Sarah spoke about her experience of distress and of being advised to seek help by a colleague at her workplace. She had experienced a traumatic incident whilst at work (as discussed in chapter 4) and had been struggling with her emotions since, experiencing flashbacks and nightmares. Upon the advice of a colleague she accessed private counselling through her workplace and so bypassed any need to visit her GP (which she felt would have been off-putting due to likely waiting lists). In this scenario, Sarah's colleague helped her identify that something was wrong, as discussed in chapter 4; the following excerpt has already been provided in chapter 4, and a curtailed version now follows:

***Sarah:** I can't think who it was.. it was one of my colleagues, who said Sarah, have you thought of talking to anybody and I said 'well who' you know and she went 'well you can through' cause she's going to somebody here at college, and she said 'well you can either speak to somebody through college or they use independent providers for staff' and I thought 'oh well I'll give it a go'*

Sarah's colleague not only helped her to identify that something was wrong, but she also provided signposting to help that was available through her workplace (it is worth noting that Sarah's colleague also attended this specific workplace counselling). Sarah was then able to access private counselling through her workplace without visiting her GP. Her experience does not count as help-seeking *via a GP* (for the purposes of this study), but it is an instance of accessing help via a different route, a route with *restricted access*. She therefore has differential access to care based upon her specific employment type.

Another of the lay participants, Kate, accessed private counselling through her university:

***Kate:** I saw a counsellor earlier on in this year at university .. cause it's free so I thought why not ..*

Kate had been experiencing a period of distress arising from some problems within her family that led to the breakdown of her parents' marriage and the ceasing of communication between her and her mother. Her decision to use counselling was based upon her easy access to it, access that is restricted solely to students and other members of the university. Again, Kate's access does not count as formal help-seeking for the purposes of this study, but it nonetheless represents access to help in the form of counselling, that reduced any potential need to see a GP for such help.

Diane talked about her own personal experience of seeking help on her niece's behalf. Her niece had been sexually assaulted whilst travelling abroad, and Diane was keen to find out about the psychological consequences of the attack and provide appropriate support to her niece, who was living with her upon return home. She carried out internet research to locate and make contact with Rape Crisis (a national charity that provides support and counselling to female victims of sexual violence), and was also able to speak to a friend of hers who was a doctor. By consulting her friend, she could access medical advice informally:

Diane: there's a friend of mine who's a doctor and said a lot of .. you know everything, that she would have nightmares or whatever and things like that so .. in some ways I then felt prepared for what might happen

Diane accessed counselling for her niece directly through Rape Crisis; she was subsequently directed there by her niece's GP (she attended a GP consultation with her niece) but by that time had already initiated contact and obtained support directly. Diane was pleased that she had done this, and not waited to receive advice at the GP consultation, as she had been able to secure help for her niece more quickly; additionally, the informal advice of her friend who was a doctor helped her to be better prepared for dealing with the aftermath of the attack. She had been able to discuss her fears and obtain advice from a health professional, with someone who knew her and was willing to take time to address her concerns.

These participants' stories provide different examples of how a network can help someone to come into care without visiting a GP; Sarah and Kate had

privileged access to counselling by virtue of their roles as employee and student respectively. Diane had access to the informal advice of a doctor, who was a friend of hers and therefore willing to provide advice on that basis. In these examples, they belonged to networks that provided differential access to useful resources, in addition to the receipt of support and signposting that was present in the help-seeking category. Kate and Sarah were able to access free counselling without consulting their GP; whilst it may be that neither of them would ultimately have sought help via their GP, their differing access (via their networks) means they did not need to attend a consultation to access *free* counselling. These examples show that these specific members of the lay group had more informal access to support than the members of the help-seeking group, most of whom were not employed, or employed in casual, manual, low paid work. Kara is an exception to this and her employment is discussed more in section 6, further illustrating this point in a discussion relating to perceived access to care. For those help-seekers who were employed, only Kara mentioned access to workplace counselling, which she then accessed after receiving her diagnosis from her GP; she did not access it prior to seeking help as she did not view herself as specifically needing any help, her GP diagnosed her as depressed and referred her to counselling.

Discussion

By including the stories of participants from the lay group, it is possible to see that certain participants had differential access to some form of support, that may have averted the need for help from a GP. This points towards a related discussion: that individuals who do not have privileged access to support or advice are more likely to have to seek help from their GP (thus feeding into statistics relating to the prevalence of problems within GP care), and that individuals who have privileged access to care may be able to access help *more quickly* because the need to visit a GP is eliminated (this is briefly discussed below, and in chapter 6). These points are significant and merit brief signposting, although they are beyond the remit of this study. Where individuals do not have access to free counselling (that is, without cost), or the advice of a doctor without consulting a GP, this points towards the possibility that statistics relating to help-seeking may omit the extent to which people

access *informal* channels of help and advice – ‘informal’ here used to denote services or advice that do not require a GP referral, including counselling and other therapeutic services that are available through direct access. Thus, individuals with greater access to resources may be less likely to require *formal* help, and to be recorded within help-seeking statistics. This is beyond the remit of the study to investigate, however it would serve as an interesting focus for additional study. Nonetheless, it is possible that those with fewer resources require more *formal* help, which may in part feed into continuing trends of *recorded* mental health problems being most prevalent amongst those with lower socio-economic status, which is a continuing trend (Marmot 2010). This is not to forward an ‘artefact explanation’ (Rogers and Pilgrim 2005, p.45) *i.e.* that the association observed between inequality and poor mental health reflects a measurement artefact alone, but rather to emphasise that social factors affect those who require *formal* help, and those who might not, which may *amplify* social inequality as well as reflect it. This may also be exacerbated by the speed at which individuals discuss being able to access such informal care. The work of Pescosolido (1992) supports the role of networks in providing people with greater ‘opportunity’ to access care. It is important to point out that it is not possible to know whether Sarah and Kate would have sought help from their GP had they not been able to access counselling (indeed Sarah speculates that she would most likely have sought help only in the event of physical problems developing, such as inability to sleep), and so this discussion relates to potential implications that are *speculative*.

The point of this section is to illustrate that a person’s wider networks – whether defined as social capital, social networks or a different definition that encompasses support and resources – affect their likely help-seeking outcome. Networks not only help a person identify that there is a problem, but also shape what resources an individual has access to, and whether they are able to receive support without consulting a GP. This therefore has potential implications relating to inequality, which have been signposted here. It may be that if an individual has access to informal (*i.e.* not via their GP) resources including workplace counselling, then the need to consult a GP for distress is reduced. This again links into recent work by Pescosolido (2011) who points out that a

person's need for – and *access to* – *formal* resources, may be shaped by their wider networks.

In addition, the role of the networks to which Freidson (1970) refers, which is to categorise an individual's distress (as potentially amenable to care) is likely to be intensified by the experience of mental health care by members of such a network (as is mentioned in the cases of sanctioning that Kara and Sarah refer to). This is also mentioned in earlier work by Horwitz (1977); it is pertinent to point out that the experience of mental health care by individuals within a person's networks, renders this type of advice more likely to be given.

The next section will now consider a person's context in relation to being within a medical setting (not related to their mental health). Specifically, I will discuss how for some people, being within medical care meant that these participants were particularly likely to have their distress interpreted from a medical perspective; their distress was at once increased by having significant and worrying health problems (*i.e.* they were enduring distressing circumstances), and their distress took place in a medical setting, rendering it amenable to observation by a medical practitioner and subsequent classification.

Prior presence in medical care: the medical 'gaze'

Having discussed how individuals' networks played a role in them coming into care, it is important to address one specific way that appeared to be salient for two of the participants in particular. For those who were in a medical environment related to their physical health, their presence in that environment rendered their distress as being particularly likely to be viewed as something that might fall under the remit of medicine. For those participants who were experiencing severe physical health problems (notably Dylan and Anna, although David's story (in chapter 3) is also relevant) they were at once experiencing heightened distress (arising from their health problems) and also their distress was witnessed and interpreted by medical professionals. The existence of severe health problems, in these cases, therefore intensifies the likelihood of having distress framed as a medical issue, because distress levels are at once intensified (by the medical problem) and also brought under a medical gaze that is likely to view such distress through a medical lens. There

is therefore a double-effect, that of increased distress and also increased susceptibility to distress being categorised by a medical practitioner. Dylan and Anna's stories both show how their physical health problems rendered their lives distressing, and were both ushered towards care by people involved in their physical care; indeed, David's story is the same. In the case of Sally Anne, this is less clear, although it is evident that she spends much time in a medical setting related to physical health problems, which meant that she was therefore more likely to ask for additional Valium (at which point she was directed towards counselling and prescribed antidepressants). Dylan and Anna's experiences in particular show that had they not been in a medical environment related to their physical health, they would not have sought help (or in Anna's case, had help sought on her behalf) at the time that they did.

Discussion

There is significant evidence pointing towards high levels of coexistence between physical health problems and mental health problems (for example, this relationship has been referred to within Government policy documents such as the previous Labour government's 'New Horizons' (DH 2009)). The data in this study point towards the possibility that presence within a medical setting renders an individual's distress as being particularly likely to be categorised as a mental health problem. This evokes Foucault's concept of the medical 'gaze' (Foucault 2003 [1973]), that is, a gaze that penetrates the body that is presented to the clinician in a medical setting, and classifies and interprets signs and symptoms according to their current medical knowledge. This is summed up repeating Armstrong's (1994) assertion given in the literature review:

A body analysed for humours contains humours; a body analysed for organs and tissues is constituted by organs and tissues; a body analysed for psychosocial functioning is a psychosocial object. (Armstrong 1994, p.25)

That is to say, because medical professionals view the body as a medical object, they are inherently likely to view extreme distress in terms of medical concepts

(*e.g.* depression); therefore, when a patient who is undergoing treatment for severe health problems is distressed, such distress may well be viewed within medical terms with associated treatment subsequently recommended. It is important to point out that this finding relates to observing the process of how distress might come to be classified as a mental health problem, or as amenable to care; it is beyond the remit of this study to consider whether such classification is appropriate or not, and it is not the intention to suggest this is an inappropriate outcome. Rather, I am outlining a process that occurs. This could potentially feed into a discussion around medicalisation – which is the process by which something comes to be viewed within medical terms – however whether this is a positive or a negative outcome for the individual is beyond the remit of this study. The process observed does relate to findings discussed by Hunt *et al.* (2009) who point out that women’s increased presence in a medical setting, related to fertility and child-rearing, provides some explanation for the higher prevalence of mental health problems amongst females (*i.e.* they do not necessarily seek more help, or experience more problems *per se*, but rather are within a medical setting more frequently and therefore likely to have their distress observed and categorised in such a way). I would extend this to include people experiencing severe health problems, who are at once likely to be distressed, and also are within a medical setting. This may provide additional weight to the recorded correlation between physical and mental health problems. This aspect of help-seeking, which essentially encompasses the way in which people who are present in medical care might be *directed* towards further care (as opposed to intrinsically seeking care for themselves), represents an original finding in this area, and merits further investigation.

Overall, this section has discussed how help-seeking is shaped by a person’s context, and should not necessarily be viewed as an individualised act. It is most likely to be the act of solely the individual, when the person is able to clearly discern a problem and the possibility of some form of help. I have discussed different ways in which a person’s context is important in helping them come into care: this is through helping a person to identify a problem (and that some help may be available); in shaping the resources available to a

person (in particular those that might be available without the need to consult a GP); and in rendering a person's distress particularly likely to be interpreted through a medical lens by being within a medical setting (whilst distress is likely to be experienced). This has fed into several sub-discussions that provide additional explanations as to why figures related to help-seeking may be as they are. It is important to point out that this section contains insight that is original in relation to the processes by which individuals come into care. Specifically, the role of the 'medical gaze' in interpreting the distress of individuals undergoing treatment for severe health problems, represents one way in which distress comes to be categorised as within a framework of 'mental health'. Additionally, the use of interpretivist qualitative data to support Pescosolido's (2011) emphasis upon the role of networks, represents an original application of this type of data to this theory within the UK.

Lay understanding and help-seeking

Having discussed the process of interpretation that has taken place amongst help-seekers, and the relevance of networks in assisting this process including signposting towards care, it is important to consider the role of lay understanding as this was one of the initial research questions. The literature review highlights the perceived importance of lay understanding in the help-seeking process, and this was the impetus for exploring any potential relationship. As discussed in chapter 4, it was possible to discern some relationship between what lay participants thought around the topic of mental health (causes of mental health problems; how one might identify and address such problems) and where they might hypothetically seek help. This section will now address the help-seekers' stories and consider what role lay understanding played in them coming into care. Analysis was carried out by examining help-seeking participants' stories as a whole, and considering what factors triggered the seeking of care, delayed it, or affected it in some way (such as participants' interpretations of their problems), and *why* help was sought at that particular time.

The relationship between lay understanding and help-seeking has been left until the end of this section, because help-seekers' actions must also be understood in light of the factors that have already been addressed in this

chapter. Therefore, individuals' interpretation of their difficulties may have played a role in the delay of seeking care (as with Dylan and Tanya), and individual's wider networks may have played a role (or not). Leading on from this, I also briefly addressed the fact that fears around physical health triggered Antonio and Patrick to seek care, and the occurrence of an adverse event affected Sally Anne and Anna (in the case of Anna's first experience of seeking help). By considering the help-seekers' stories alongside their own interpretations, it became clear that the seeking of help depended upon specific factors, according to the experiences of *this study's* participants:

- their own interpretation of their distress – and this was related to whether their circumstances provided sufficient 'justification' for their distress (*in addition to* their lay understanding)
- the sanctioning of others (including medical professionals)
- the occurrence of a crisis (*i.e.* the sudden worsening of their distress)
- the occurrence of an adverse event (such as Anna's accident, and Sally Anne's 'fracas')
- fears around their physical health

These factors played the most immediate role in the help-seekers coming into care, according to their stories. Help-seeking was frequently initiated following a crisis of some sort: whether an interpersonal crisis (such as Tanya's) where distress built up to a point of desperation, or a serious and adverse event (such as Anna and Sally Anne). The seeking of help therefore became more a matter of urgency than a matter of reasoned action (such as Antonio's) and I will discuss this in chapter 6 where I address the limitations of viewing help-seeking as *purposive action*. For now, it will suffice to say that when experiencing distress, individuals' help-seeking was affected by the events surrounding it, as well as their own ability to interpret and cope with their distress. No participants discussed their help-seeking in relation to having identified some sort of mental health difficulty within themselves; no one linked their beliefs around mental health to their actions. In the participant validation stage, this *was* applied as a framework post-help-seeking by Cath, who said that at the time of seeking help, she saw no such link between her

actions and her understanding around mental health, although in hindsight, she can see a link. Nonetheless, this was not in relation to her seeking of *formal* care, but rather it was in relation to her spending much time discussing her problems with close friends, which she now views as a form of counselling.

One way in which lay understanding *may* have played a role is in relation to a lack of awareness around mental health; Dylan and Tanya both state that they knew very little about the topic of mental health at the time of their distress, and this *may* have impacted upon their lack of recognition of any specific problem, other than their extremely distressing circumstances. However, as discussed, they were both also experiencing very distressing circumstances that provided justification for distress to be present, thereby rendering the process of ‘normalisation’ particularly likely; their actions have to be viewed with *both* these factors in mind.

Discussion

Bearing in mind the link between lay understanding and hypothetical help-seeking, it is important to consider why there might be a less clear relationship in an actual help-seeking scenario. Based upon the data in this study, it appears as though actual help-seeking is a product of a number of different factors mentioned above; that is to say, the intensity of a person’s distress (and the role of crisis in bringing them into care), a lack of interpretation that there is a problem, the advice of others, and the life events surrounding an individual (such as Antonio’s concern around being able to be fit and well for the arrival of his second child). Literature points to the salience of individual’s social worlds in deciding when to enter care – indeed this is the key finding of Zola’s (1973) early work – and this appears to remain relevant to the individuals’ stories, along with the experience of distress and their attempts to cope with it. This differs from hypothetical help-seeking, which cannot realistically predict how their distress might interact with their wider lives; hypothetical help-seeking is, literally, drawing upon theories to predict action, as opposed to the lived experience of distress which was very much a part of help-seekers’ wider lives. Lay understanding may play *some* role, but this is in addition to other, more immediate factors related to their wider lives, and their social context.

Where Dylan and Tanya both expressed that they didn't know anything about mental health (or relevant services), Jorm's (2000) concept of mental health literacy is potentially relevant. It is not possible to know to what extent a lack of understanding around mental health played a role, nor to what extent the individual's ongoing distressing circumstances rendered the identification of anything other than their circumstances as being wrong (although this is given as an explanation for not recognising that something was 'wrong'). However, it is likely that the combination of extreme and ongoing difficult circumstances, *and* lack of awareness around mental health, played a role in neither participant recognising that their distress levels were in themselves problematic. The potential relationship between lay understanding and help-seeking provides the impetus for campaigns aimed at increasing awareness around mental health. Recent work (Yap and Jorm 2012) continues to argue for benefits of improving mental health literacy and its potential effect upon help-seeking, whilst acknowledging the potentially limited impact that increased awareness might have upon seeking professional help. This relationship continues to evade researchers, even in the most recent of research; for example, Yap and Jorm (2012) concede that awareness of appropriate action is only one aspect of the process of helping an individual come into care (or indeed, helping oneself). This study has helped to provide insight into some of the *limitations* of lay understanding in relation to help-seeking. Lay understanding is mediated by other, more immediate factors in a person's life, however, lay understanding *does* play some role in the advice that might be given to a person in distress. The nuances of providing advice and support have been discussed in the previous chapter, illuminating the 'lay referral network' (Freidson 1970) whose role was discussed in this chapter, alongside which help-seeking decisions are made.

Understanding around mental health therefore does inevitably impact upon the *advice* that distressed individuals might receive; that is, lay referral networks comprise people who have views about mental health. In addition, where members of a person's network have themselves received some form of therapy or help, this may render them more likely to advise that specific course of help to others (as with Sarah's recommendation by her colleague). This was mentioned by Horwitz (1977) many years ago (he referred specifically to

people who had received *psychiatric* help) and remains salient in relation to other people's experiences of counselling potentially feeding into this being recommended to others. Therefore, lay understanding does play a role in shaping the kind of help that might be offered, along with the personal experiences of help that lay referral networks might have had.

Despite the importance given to the meanings attached to illness in recent research, the data reiterates the non-individualised way in which help-seeking should be viewed. Married to the pressing circumstance that have been illustrated as pivotal in help-seekers' stories, individualised notions of help-seeking (that draw upon notions of purposive action, and of interpretation that *leads* to action), fail to account for the contextual nature of help-seeking that has been illuminated.

In addition, Bury (1997) discusses the fluid nature of lay understanding and urges caution against assuming that it is possible to discern a logic connecting knowledge (or beliefs) and action, and Blaxter (2010) echoes this point. The limitations and applications of the concept of lay understanding need to be acknowledged when investigating help-seeking; an individual's context plays an important mediating role in affecting interpretation and subsequent outcome.

Conclusion

The data provide insight into the complex process of interpretation that takes place within individuals and in tandem with their wider networks, that may culminate in an individual coming into care. Difficulties may arise when normalisation takes place and this has shown to be particularly problematic when individuals are experiencing extremely distressing circumstances for which significant distress is to be expected. The data provide insight into how the networks around an individual may come to play a role in bringing them into care. The networks define the resources available to individuals (including privileged access to certain types of care) and show participants' actions less as an individualised response to distress, and more of a socially situated, and socially mediated response to problems that are inseparable from the social lives of the individuals. The data therefore supports a move towards a less individualised approach to understanding help-seeking. Whilst some help-

seeking takes place without the help of others, an approach is required that takes into account the heterogeneity that exists amongst help-seeking stories; theories relating to help-seeking must take into account this heterogeneity. Models that assume simple differences in intention, or need or propensity to seek help are too simplistic to account for the diverse patterns that are present in primary care, as discussed in the literature review. Pescosolido's Network Episode Model (NEM) Phase III (2011) proposes a model that takes into account all aspects of an individual's context, from their biological predisposition through to events in their illness career, their personal network and the community context in which they live. As Pescosolido and Boyer (1999) point out, models that account for illness behaviour are gradually cohering towards a similar, interdisciplinary perspective where no one aspect of an individual's circumstances is assumed to account for their illness behaviour or outcome. Rather, Pescosolido (2011) proposes a complex interplay of forces that goes beyond biopsychosocial explanations and includes an individual's personal networks and the organisational context in which they live. This forms part of a shift in studies of help-seeking behaviour towards an acceptance that a variety of factors, internal and external, must be taken into account simultaneously. The data in this study support such a shift, bringing data – that is derived from an interpretivist UK-based study – to bear on theory that is derived from a mixed methods, larger-scale approach.

In considering the stories of help-seekers, I have focused on the ways in which participants interpreted (or not) their need for help. This involved focusing on two participants' stories in particular, as they showed specific delay in seeking help and specific problems in interpreting that there was indeed a 'problem'. In doing this, their stories have highlighted the increased potential for normalisation of distress when individuals are experiencing very distressing circumstances. I then examined the process of coming into care, and how individual's stories are shaped by the people (and resources) around them. Help-seekers' stories sometimes involved the interpretation and action of others; in particular, the experience of physical health problems places individuals in contact with medical professionals who may interpret distress through a medical lens and recommend help-seeking. This has implications for understanding potential differences in help-seeking figures between different

groups of people, and may also contribute to increased medicalisation of distress. Existing research into help-seeking provides evidence of contrasting patterns, and has sought to understand why some seek help and not others. This study has shed light on how potential nuances of individuals' networks and accompanying life circumstances might render them more or less likely to seek and require formal care. The data lends support to research that help-seeking is increased because of presence in a medical setting (the example given in the literature review is of increased female help-seeking due to presence in a medical setting related to child-bearing and/or contraception (Hunt *et al.* 2009, Hunt *et al.* 1999)).

By including experiences of help-seeking that took place in the lay group, I have been able to demonstrate that some within the lay category have obtained help through routes other than consulting their GP. Indeed, inclusion in the 'help-seeker' category was contingent on having sought help through a GP, and it was hoped that within the lay group it may be possible to access stories of people who have not sought help (via their GP) but who have experienced distress nonetheless, to see what differences there might be. This has shown that for the lay participants in this study, their contexts provided access to resources that were not open to all.

This chapter has also shed light on the limitations of lay understanding in shaping an individual's help-seeking. Literature suggests that lay knowledge plays a role in help-seeking, although there has been a paucity of research examining this in relation to mental health in the UK. The data illuminate the difference between hypothetical help-seeking (as discussed in chapter 4) and the reality of help-seeking whilst experiencing distress.

The next chapter will address what specific expectations of care were present amongst help-seekers and lay participants, and indeed whether expectations played a role in help-seeking. The chapter will consider how expectations of care (where present) might interact with what is available within a GP consultation, so that the wishes and expectations of individuals can be considered against the reality of care.

Chapter 6

Expectations of GP care

This chapter focuses upon expectations of GP help. This takes place in two different ways – by examining the *role* and then the *content* of expectations. I will begin by considering the expectations of help-seekers and whether these played a *role* in determining help-seeking behaviour. This is with the intention of providing some insight into whether help-seeking reflects specific expectations of care, and whether this might be indicative of medicalisation of distress. The findings indicate that specific expectations of care do not drive the seeking of help, except for those who have already received care and whose interpretation of distress has already been framed by a medical professional.

I will then address the *content* of expectations; I will begin with an assessment of lay participants' expectations around help (having already considered help-seekers' in the first section), followed by what both groups *would like* to receive from their GP (if different). The findings will then be contrasted against the reality of service provision, in terms of the help that help-seeking participants received, in order to elucidate where incongruence might lie. This provides useful insight into the content of expectations, and allows for consideration of whether expectations might be met. From both groups of participants there is an expressed belief in the importance of meeting other people who may have shared a similar experience, so that they may be able to share experiences and relate to others, receive advice on how to cope and find out that they are not alone in having their experience. There is also some level of expectation that GPs are able to provide such signposting, but the realities of service provision appear to be different despite the potential for such referrals in the process of stepped care (NICE 2011a). There is therefore a potential lack of signposting to a specific type of help that individuals may desire, and that individuals may find less stigmatising than psychological therapies, which were viewed with fear by some participants. The study also sheds light on how participants view the care that GPs are able to provide, and

highlights specific aspects related to perceptions around the delivery of care that might deter individuals from seeking help.

The chapter follows the structure of previous data chapters, by providing data and analysis for each theme, followed by a discussion of its applicability to literature.

The role of expectations within help-seekers' stories

The research questions given in chapter 3 address whether the study usefully contributes to elucidating theories relating to help-seeking. Dingwall (1976) suggested that help-seeking is a form of *social action*, that is, action that is intended to produce specific outcomes bearing in mind its social context (Hollis 2002). However, as a counter to this, Pescosolido's (1992, Pescosolido *et al.* 1998) research demonstrates that for many individuals, help-seeking does not reflect 'rational' or purposive action but is rather a complex interplay of chance events, and 'muddling through' (Pescosolido *et al.* 1998). However, as this study sought to consider whether medicalisation of distress is taking place prior to seeking help, and potentially driving demand for care, there remained a need to consider participants' expectations of care and whether these played a role in the seeking of care. This section will therefore perform this task.

The data indicate that participants were not specifically motivated by expectations of help, although such motivation was more apparent amongst participants who had already sought help in the past. For these more long-term help-seekers, their expectations had been framed by a medical response, and their current patterns of help-seeking are in line with the help provided by services. However for individuals who were seeking help for the first time, expectations were less apparent and, in some participants, were absent all together. The extent to which purposive action is an appropriate framework is *limited*, and most closely applicable to those who already have experience of services. This section is based upon an assessment of *participants' expectations*; it must be conceded that expectations offer only one port of entry into the concept of medicalisation and of purposive action, however expectations are nonetheless useful to consider as drivers of action. I will address the ways in which expectations differed between participants.

No specific expectations: 'just in case'

Some participants held no specific expectations around medical help and did not necessarily expect any help to be available. That is to say, the GP may be able to help, or may not; there was no expected outcome. For such participants, attendance at a consultation can either represent *another step in a process of elimination*, or a chance visit *just in case* a doctor is able to help or explain. They perceive something as being wrong but do not know how to address it. This shows some level of grappling with the idea that medicine *might* be able to help, but does not imply that this is wholly expected or purposeful – it represents part of the participant's attempt at interpreting and trialling solutions. For example, for Cath, help-seeking represented the culmination of a *process of elimination*, as discussed by lay participants who seek to deal with (or eliminate) the causes of distress before treating distress as an entity in itself. She had already engaged in practical attempts to address the causes of her distress (the ill-treatment of her by her employer) and only consulted her GP when there was no way of resolving the cause and she had run out of other avenues: 'so I didn't really know what other option I'd got' (Cath). She was experiencing continued distress and, once unable to eliminate the cause of it, she sought help to deal with the distress instead. Having tried the other resources available to her, her GP represented a different type of resource; her process of elimination culminated in consulting her GP *to see if anything can be done*. I am placing emphasis on this last point to underline that she may not have expected a GP to be able to help, but rather she went 'just in case', the subtext being that it is up to the GP to decide if they are able to help. Cath describes not having any expectations:

Sue: when you went to your doctor ... did you have an idea of what you know you felt that you wanted in advance

Cath: no I didn't really no I just .. well I don't know I don't know whether I'd expected him to give me some tablets [laughs] I don't know what I expected I just went and um .. I think I said to him I don't know what you can do and then I think I burst into tears [laughs] .. and it all came out and um ... but yeah

Her GP was able to help by giving her time off work in which she was able to escape the cause of her distress and regain sufficient strength to return to work and subsequently find new employment. For Cath, medicalisation of her distress only took place when the other options available to her had proved inadequate. Cath's is the only example of a *process of elimination* amongst the help-seekers, although this type of response was also common amongst lay participants; the notion of help-seeking as 'just in case' also ties in with some views expressed by the lay public, who define a process of elimination of addressing the causes of distress first, only *resorting* to consulting a GP when nothing else has worked. This reflects an approach that attempts to deal with the perceived life circumstances *underlying* the problem first, before addressing distress as an entity in itself. This approach avoids labelling problems as 'mental health' without trying other avenues first, either because there is a wish to avoid this label (as discussed in the chapter 4), or because this label does not come to mind until other options have been tried. The application of a medical framework may therefore be as a *default* category, one into which problems are swept that cannot otherwise be easily solved based upon a person's current resources. Even though this type of help-seeking was mostly voiced in the lay group, Cath's example usefully illustrates its applicability to actual help-seeking; the implications of this will be addressed in the following discussion section, and also in the last section of this chapter.

Kara's story indicates that she did not think she had a problem until she went to her GP for help with her sleep problems, and her GP interpreted her experiences as stress and depression, and possibly post traumatic stress relating to her experience of domestic violence in her childhood. Kara did not view herself as having a problem, other than problems with sleep, as mentioned in the previous chapter. She has a history of specific periods of engaging in risky behaviour; she did not see this as a specific problem, other than having to deal with the consequences of her behaviour (such as ending her relationship). However, during the consultation, and at a time when Kara's risky behaviour was starting to re-emerge, she broke down in the consultation and said she couldn't cope. Until her GP reframed her experiences for her, Kara says she had no idea that her problems were in the category of mental health. Whilst there is some contradiction in her story – that is to say, she said that she didn't

think she had a problem, and had no intention to speak to her doctor, but at another point she alludes to concern about having her child taken away from her, and to the stigma of being ‘packed off’ somewhere – it is apparent that a reframing of her experience took place nonetheless. She moved from a point of having no expectations of help, and of viewing her behaviour simply as ‘her behaviour’ to a different interpretation where she understands these risky behaviours (including heavy drinking, drugs and promiscuity) as *coping mechanisms*. I include different excerpts to show this unfolding, from expecting to be dismissed without help, to viewing her experience through the framework of mental ill health:

Sue: could you tell me a bit about when you made the decision to go to the doctors could you tell me a bit about the kind of .. the process the thought processes that you went through and the journey

Kara: well there wasn't one .. there wasn't one .. it's really weird because I didn't think I had a problem and I walked into the doctor's just to .. talk about my sleep deprivation because I walk in my sleep, I'm quite a weird sleeper ... which is also due to that um .. the whole reason why I'm stressed and depressed ... um .. I went in there for my sleep deprivation and I just broke down and said I couldn't cope no more, it wasn't even premeditated to go in there and talk about that it just ... I just started crying and said I couldn't cope and I think that was it ..

Since that appointment (roughly two weeks prior to the interview), where she was prescribed antidepressants and referred to counselling, she had been able to access counselling through work (she had attended one session) and had begun to view her experience through a new lens. When asked later about her expectations of help she responded:

Sue: did you have any particular expectations when you went to the GP did you have did you have any [Kara begins to answer] ideas

Kara: I was expecting them to say there was nothing wrong with me and to go home to be quite honest with you .. um .. the last time I went and tried to moan about anything that was wrong with me um [...] which I've

put down to the stress I was bloating out and I looked 9 months' pregnant [...] and it was just 'there's nothing wrong with you, it's fine' and I sort of expected .. I sort of expected to be .. I don't know kind of shoed off ..

When asked if she had tried alternative routes to relief from distress, her response reinforces that she didn't think she had a problem and so could not have tried other ways of dealing with it:

Sue: have you turned to like alternative therapies or um kind of like ..

Kara: to me I didn't have a problem until last week...[hear: 'ah yep, I'm with you'] so .. that's .. to me that was it .. all my .. I didn't know these was coping mechanisms till I understand that I was in a bad place and I was .. I've become completely .. I know it sounds daft because it's only been a week but I've become completely aware of all my behaviour everything .. and why I did things, everything's explaining itself in my head and .. I've stopped feeling ashamed now as well because ... I had good enough reason .. to react like that ..

The excerpts from Kara's story are used specifically to illustrate that she had no specific expectations of help (despite some contradiction within her story), and that because she didn't perceive herself as having a specific 'problem' (at least, not one that she could understand or define, other than feelings of being unable to cope and problems with sleep) she had no reason to seek help sooner. Her seeking of help resembles a 'just in case' approach, one that is echoed in the lay group and has commonalities with Cath's. She seeks help for physical symptoms alone, although is pleased when her feelings of being unable to cope are met with understanding and a solution. What is pertinent to consider here is that whilst Cath and Kara's attendance in a GP consultation can be viewed as presentations of distress or somatic symptoms, they do not specifically evidence medicalisation of distress on their part; that is to say, they did not necessarily expect medical help or view it as appropriate until it was offered. Medicalisation takes place when a medical *response* is given, and not before; prior to a response being offered, participants did not necessarily see their

problems in terms of being amenable to medical help. Whilst participants' distress could not be medicalised without being brought into a medical setting, the GP completes the process by offering a medical response to their distress. This is discussed more in the last section of this chapter.

As discussed in the previous chapter, Dylan sought help upon the advice of a consultant who was treating his arthritis. He was pointed in the direction of help by his consultant; he visited his GP partly because he had become aware that there had been significant changes within himself, and partly because he was obeying his consultant's instructions. Dylan did not have any expectations of mental health services, as he didn't know anything about them nor about treatment in general (as discussed in chapter 5), and indeed was only attending upon the advice of others:

Dylan: Experience about going to see doctor and specialists and everything like that has been perfect I can't really grumble on the service ... 'cause I don't know what to expect anyway and they've been helpful, do you understand what I mean

He had no expectations of help as he knew nothing about mental health services, and indeed he later expresses concern as to whether his help-seeking will indeed prove beneficial or not:

Dylan: sometimes well...I'm seeking help now and I think ... oh.. is it gonna be any better for me in the long run.. or is it just gonna be a short term thing ... which I don't know yet you know what I mean .. until I start going through all these counselling meetings getting everything sorted out, then I'll know in myself

As mentioned in chapter 5, Dylan did not interpret his distress through the lens of mental health, but rather he had been experiencing multiple social problems (unemployment and lack of housing) and chronic health problems and assumed this his distress was simply something he had to tolerate. His seeking of care does not reflect any therapeutic expectations, but rather is done upon the advice of others, who themselves might have expectations around the suitability of

care through a GP (in particular the hospital consultant who advised him to seek help, as I point out in chapter 5). His experience was therefore different to that of Cath and Kara's, however it remains pertinent that he had (and still has, at the time of interview) no specific expectations about the suitability of mental health care.

Fears around physical health

As discussed in the previous chapter, Antonio and Patrick both sought help due to fears around their physical health. Patrick contacted his GP because the symptoms of his panic attack (increased heartbeat and raised blood pressure) potentially resembled a heart attack, something that he is at risk of having; he was given an emergency appointment. He was aware that his experience was potentially a panic attack, but was too afraid of dying from a heart attack when experiencing these symptoms, to interpret them otherwise. He was specifically seeking emergency care relating to his health, including assessment of his condition and whether he is having a heart attack or not. He does not therefore have any assumptions in relation to the suitability of care in relation to his *mental health*; rather, it is his physical health that is at issue when seeking care.

Antonio went to his GP specifically to receive advice about whether his stress levels and associated headaches might have a detrimental effect on his physical health. As mentioned in chapter 5, he has been unable to relax since the death of his mother, and finds himself feeling very tense (including physically, *i.e.* he is unable to achieve a relaxing position whilst sitting on his sofa) and suffering headaches. His main concern, and reason for seeking help, was that his stress levels (and the associated headaches and physical changes) might have a detrimental impact upon his health at a time when his wife was pregnant with their second child and he needed to be physically well and able to work. Whilst his concerns were mainly relating to his physical health, he did hope to be referred to a group where he could meet others who have shared a similar loss and share coping strategies. His reasons were therefore twofold: to receive advice and reassurance about his physical health, and to receive referral to a suitable group where he can meet others in a similar situation (which he expressed during interview, although he did not say that this had been voiced during his GP consultation). This second aspect does entail a consideration of a

certain type of support, and so does potentially fit into a framework of purposive action, however he expresses this as a secondary concern to his health. He did not think a medical response was necessarily suitable to his distress, but rather he felt that his GP would be able to refer to some form of social support. The existence of dual drivers of action must be borne in mind. (I will address the relevance of his wish to meet others later on in this chapter).

In both these examples, participants' main fears were health related, and thus their GP was the 'obvious' port of call. Neither was seeking help for their distress *per se*, but rather for reassurance about their health and potential signposting. Their help-seeking was first and foremost to receive advice about their *physical* health, in full awareness of their own distressed states. Their main expectation was not, however, to receive a medical response for their *distress*; their seeking of help is therefore not viewed specifically as framed by expectations of care, other than that the care of *physical* health is within a GP setting. Antonio had hoped for some sort of signposting to a support group, as he views his GP as someone who should have access to such information and to be prepared to provide signposting. This *does* reflect action based upon an expected outcome, albeit a minor part of his reason for consulting.

Patrick's example is interesting as he has prior experience of mental health care; he has been taking antidepressants since his wife's death and his subsequent diagnosis of prostate cancer. I will argue below that previous experience of mental health care frames participants' expectations of help and provides the clearest demonstration of purposive action, linking expectations of care and help-seekers' actions. However, in this instance Patrick does not seek care in relation to his mental health, rather he seeks reassurance from his GP in relation to his *physical* health.

Previous experience of services: the framing of expectations

Some of the participants did have specific expectations of help from their GP, and this is most in line with the notion of purposive action mentioned above. This could be applied to four of the participants, three of whom are notably long term mental health service users and whose help-seeking has been informed by previous contact with services. The longer term mental health service users are Tanya, Anna and Debbie; the newer help-seeker is Sally Anne.

All attended their GP with some specific intended outcome in mind that bore resemblance to what is available through GPs and secondary care; they all attended a consultation with the intention of receiving a certain type of help.

Tanya had been advised by a privately consulted psychiatrist (relating to a claim for compensation) to ask for a referral to psychotherapy, a referral that the psychiatrist felt to be the most appropriate course of action following a detailed assessment and interview. Tanya consulted her GP seeking out the referral:

***Tanya:** I took it [psychiatrist's report] in I think, I think I actually took it in, I think it was 'Dr Freeman' and she read it out and I said 'this is the way he thinks I should go can you do anything about it for me' and she said 'yeah I'll put in for it for you' and she put in for it..*

Tanya's help-seeking is upon the advice of another mental health professional, however she also talks about her help-seeking on other occasions and suggests that she seeks help from her GP after the experience of any mental health crisis, and it is at this point that she is able to receive advice and support about what has happened to her. She finds visiting the doctor very reassuring when she has been experiencing difficult inner feelings.

Anna had been experiencing an intensification of her suicidal thoughts recently. She and her partner both felt that she was becoming a danger to herself and that she needed further therapy. She therefore went to her GP to ask for a referral to a psychiatrist, whom she felt would be able to advise the type of therapy that would be most appropriate. She did not have a specific therapy in mind although she is aware of the different types of therapy that are available in the county and had a preference for 'one on one psychodynamic therapy' (Anna):

***Anna:** I was .. potentially looking at one on one um .. therapy, psychodynamic therapy probably um .. because I think that that would .. I think that that would probably be the most helpful for me at this time um .. there are other therapies that could potentially be useful but they're not available in this county so ..*

Anna shows significant awareness of the formal resources that are available, based upon her own internet research and that of her partner, along with their own experiences of mental health services.

Debbie was recruited through mailshot, and so had not recently sought help for psychological distress, but as a long-term help-seeker she was happy to discuss her use of services. She describes consulting her GP only when her strategies of self-management have not worked. That is, if she begins to experience panic attacks, or periods of depression, she will engage in activities to distract herself and waits until a few days have passed; whilst this summary potentially conjures up what Radley and Billig (1996) would categorise as a public account of ‘social fitness’, this type of analysis would be a digression here, although is worthy of acknowledgment. She describes her desire for a ‘quick fix’ when experiencing distress:

Sue: and when you do go to the GP, what is it specifically that um you hope or you want them to do

Debbie: firstly and I think it's probably the same for everybody .. we all want that sort of like .. try and get that instant fix you know .. so straight away you want them to give you the antidepressants.. 'cause you want to start feeling better it's .. 'cause it's a horrible feeling it's a horrible experience it's horrible to live with ... you know you do want that quick fix .. but again I mean would it be better if they could, if there was some other way without just going straight onto the antidepressants I don't know .. bit difficult .. but that is what you want initially

Debbie therefore describes her help-seeking as occurring when her difficult feelings are not passing, and at this point she specifically wants immediate help from her GP in the form of antidepressants (based upon her previous experience of receiving them) – she does seek a ‘quick fix’.

Sally Anne recently went to her GP to obtain Valium, which she had been taking on occasion upon the advice of a different GP, following a ‘fracas’ that caused her significant distress. She was previously taking Valium on the occasions that she felt she needed to and liked to have the autonomy to do so; she wanted to be able to continue with this degree of autonomy:

Sally Anne: I was at the doctors and I said .. and it was a different doctor and I said 'would you prescribe me some valium' and they said 'I don't believe in that.. I'll send you to the counsellor' ..

Sally Anne's help-seeking, although relatively new, was in order to obtain additional medication for her to take when she felt unable to function as well as usual. This was therefore repeating her experience of previous help.

In the example of Patrick given above, he too had previous experience of help, yet his actions were categorised as relating to fears around his physical health, in this instance. It is possible to see that his action may also have reflected previous experience of help from his GP, such as the receipt of Valium, but it is likely that his fears around dying were the most decisive factor thus his experience was not categorised as belonging to this section.

The participants described in this last section all had some form of desired outcome in mind that bore relation to the services on offer. Most notably it is the participants who have a long history of treatment within mental health services who show the most understanding of what they wish to receive. Having discussed the different categories above, it is salient to refer to the interview held with one of the GPs that was mentioned in chapter 2. GP interviews did not form a significant part of this study, however one particular interview provided useful insight into this area of study. When asked what she thought that help-seekers wanted when they attended a consultation, Katherine responded that she didn't think they knew what they wanted, but were consulting more out of a sense of crisis than of requiring a specific form of help:

Sue: what do you perceive that help-seekers want .. what's the range of things that people want

Katherine: I think a lot of people don't know what they want when they come, they haven't really thought through quite why they're coming they're just saying 'I feel distressed' and they .. um what we can offer is just talking, sick notes, drugs and referrals .. and that's the way I see it I don't know if that's the way they see it .. I don't think they know what they want most people .. they just come for a chat, sometimes it is a

sicknote or some people who've had drugs before want them again .. not many people want a referral to a mental health worker or .. don't particularly think that counselling would help them that's rarely something that's asked for .. but we may be able to persuade somebody that it could be helpful

Katherine's sense that patients are attending without a clear idea of what they want, or an understanding of what is available, supports the different 'types' that I refer to above (although 'fears around physical health' is not present in Katherine's illustration). She usefully illustrates that the seeking of help does not necessarily appear to reflect a desire for *medical* help, other than advice and 'chatting'. I will now discuss the salience of these different 'types' of help-seeking to a framework of purposive action, and prior medicalisation of distress.

Discussion

The notion of framing that De Swaan (1990) discusses, and indeed Dingwall's (1976) concept of social action, is difficult to perceive overtly in the participants' stories, with the exception of those who have already had their problems framed by some form of mental health care. Blaxter (2010) points out that once a pathway has been accessed by a patient, and that pathway has provided some resolve, then that pathway will be followed in future similar events. This provides some explanation as to why those with longer histories of contact with mental health services seek the most specific forms of care, and why those with none, or less, prior contact have more vague expectations (or none at all). Those with an understanding of mental health services seek to use them in ways that they perceive to be beneficial. Those whose views regarding their distress have been shaped by the receipt of medical care, are the most likely to have a medicalised interpretation of their distress. Medicalisation, or purposive action, fall short in explaining the newer help-seekers' behaviour, but rather theirs is the outcome of a combination of events, including using other resources to address their problems, attempting to cope without help, and receiving advice from others.

Newer help-seekers have not specifically medicalised their problems in advance of consulting a GP, that is to say, they have not assumed that a medical framework is the most appropriate or that a medical response will help. Rather, attendance at a consultation is part of a process that involves ‘muddling through’ (Pescosolido *et al.* 1998) and trial and error in attempting to address their problems. Rather than viewing a discernible link between participants’ lay understanding and their subsequent consulting behaviour (a link that is *implied* when considering the role of lay understanding in help-seeking behaviour, as discussed in the literature review), participants did not necessarily have an understanding of their ‘problem’, or any expectations of care. This chimes with Williams and Healy’s (2001) findings that individuals held ‘exploratory maps’ as opposed to ‘explanatory models’, and that rather than having a fixed view of their illness (and associated help), there was instead a range of possibilities to which they were open (of which GP care was one potential avenue). Indeed, the work of Pescosolido argues against an assumption that help-seeking necessarily reflects ‘rational action’ (Pescosolido 1992, Pescosolido *et al.* 1998) – action that reflects a person’s reasoned deliberations – and rather suggests that many individuals pass through haphazard journeys to care.

This goes against the idea that distress is necessarily being ‘medicalised’ – medicalised being used here in the sense that individuals are choosing to view their problems through the lens of medicine and that therefore the seeking of help reflects increased *demand*. Rather, the data supports the idea that individuals who have already experienced some form of mental health care might specifically seek medical help in the event of distress, whereas those who are newly distressed have a less clear pathway towards care. GPs may be consulted ‘just in case’ their problems are amenable to medical help, but with the implication that medical help may also *not* be appropriate (and it is for the GP to decide which). This may nonetheless feed into increasing medicalisation, in that each new help-seeker’s distress *might* come to be viewed through a medical lens on future occasions; however this does not necessarily reflect the prior medicalisation of distress by new help-seekers. This will be discussed in more detail below, in the last section of this chapter. Whilst Shaw and Woodward (2004) argue that patients pre-professionalize their symptoms (in line with De Swaan’s (1990) proto-professionalization), this does not resemble

the action of new help-seekers in this study. The excerpts from Kara's interview are particularly interesting as they show her starting out as a new help-seeker with few expectations and a fear of being 'shooed away', and then within the course of the consultation (and one subsequent counselling session) the doctor's response reshapes how she views her problems. She left the consultation with a different view of her problems and a sense that her suffering has been validated. She describes how the consultation, and her subsequent counselling, has reshaped how she views her problems and her own behaviours and how she now views her previous risky behaviours as a 'coping mechanism' whereas before they were simply her 'behaviour'.

In Cath's example, she sought help when she was unable to eliminate the cause of her distress, which was the ill-treatment of her by her employer; she consulted her GP when she felt she had run out of other options, these other options comprising attempts to resolve the hostility that was occurring at her workplace (by her employer). In this instance, her GP became an option that resembled more a 'last resort' than a choice that was based upon her interpretation of distress. When she had no alternative resources to draw upon (that is, resources in the *social world* upon which she might be able to call, such as the intervention of senior colleagues that proved unsuccessful), she turned to medicine to see if help might be available and this was given in the form of time away from the hostile environment. This reflects what participants in the lay category also discussed in relation to passing through a process of elimination; participants discussed attempting to eliminate the causes of distress and only resorting to medicine if these failed. Such an approach applies *social responses to social problems*, until there remain no alternatives; whilst on the one hand this is a useful counter to the over-medicalisation of distress, this could potentially delay the seeking of care for people whose distress or difficulty is not appropriate to such a response. This does also point towards the increased likelihood of medicalisation of distress for those who have fewer resources in the social world and require more help within the realm of medicine *i.e.* the issue of inequality re-emerges (which there is not space to address here). In addition, the issue of social problems within primary care that has been well documented (Chew-Graham *et al.* 2000, Popay *et al.* 2007a, Popay *et al.* 2007b) is also potentially relevant, although is too large a

discussion to enter into here; however it is important to point towards its salience.

The *content* of participants' expectations: what would participants *like* to receive, and what do they think is *available*?

This section will now address the content of participants' expectations – that is, what they think is available and what they would *like* to receive (if different). This is to provide insight that has immediate and practical relevance to the provision of services, enhancing the potential utility of the study for its non-academic sponsor. I will address the expectations of the lay group as a whole, including whether they would feel happy to engage with different treatment options, and will then consider how the help-seekers felt about the response that they received. I will then follow this with a specific section on one aspect of help that some members of both groups suggested they would *like* in the event of distress, as this has particular salience to current healthcare delivery.

What help do lay participants think is available from a GP?

Members of the lay group were asked to discuss what kinds of help they thought were available from a GP. This was asked as a separate question to what they thought would help someone experiencing mental health problems (if different), and I will address the responses to this latter question below (this was also briefly addressed in chapter 4); the focus for this section is specifically what individuals thought would be available through a GP consultation, to provide some insight into potential expectations and whether these are aligned with what is available.

There was a common sentiment that participants would expect their GP to be able to assess their difficulties and refer them to *appropriate* help – the role of gatekeeper (though this term was not used). GPs were frequently viewed as the 'first port of call', able to confirm whether a problem was medical (or could be helped with medicine) *or not*, and then knowing to whom a referral should be made, providing *advice* as well as *access* to specialised help. Expectations around referral were largely relating to secondary care, whether specified (*e.g.* a psychiatrist) or unspecified (*e.g.* 'somebody else who

can give you some help' (Anita)). GPs were not necessarily seen as being able to provide the most appropriate care, but were seen as being able to classify problems accordingly and direct towards the most appropriate care. A less common expectation amongst the lay group was that GPs are able to refer to community groups or self-help groups. I have included excerpts of data from help-seekers where themes appear within both groups, to provide additional support for the salience of such themes.

In terms of help that is perceived as available through a GP, most participants expressed a dislike towards medication. This was due to fears around addiction and fears relating to the alteration of personality, for example:

Sue: and so when you talk about medication as being something you just wouldn't want to engage with can you tell me a bit more about why

Michelle: I just hate the idea that you're dependent upon this one pill that you have to take every day, and once you start when do you stop, and even if you do stop, you might not actually have the mental health disorder any more but you might start acting out the symptoms because you're so worried that you're not gonna have it, have this pill, that I would just hate this chemical to be what my life is .. that's affecting, my personality I think that's such a .. it's so dangerous and you don't know what it's going to do to you in the long term, if you're on it for six months and it might affect you for like, six or seven months [...] and there's just so many side effects and so many dependency issues that it's just something that I'd really like not to have to do if possible

In addition, medication was potentially seen as not addressing the underlying problem, but rather it was seen as a palliative:

Sue: you said about drugs that you didn't think medication like wasn't very useful um .. can you tell me a bit more about that

Sadie: just for me I don't think it would um [...] I can't see a tablet helping me to be honest, not not with mental health..I can't see.. yeah if you're ill .. you know antibiotic or a paracetamol but I can't see how a tablet would make you feel better, if you was feeling depressed about

*something in your life only **you** can change that do you know what I mean, if you've got a bad relationship only I can change that by physically doing something to make it better .. I don't think taking a tablet would help I really don't [...] I can't say that for everybody but they wouldn't be for me, maybe they do work for some people but not for me, no not for me [emphasis in participant's speech]*

GPs were seen as providing access to counselling, which was viewed positively. However, when asked how participants might feel if referred to psychological therapies, a frequent response, particularly amongst the older participants, was one of fear; participants indicated that being offered psychological therapies implied that they must be 'mad':

***Sue:** if a GP were to offer you psychological therapies how would you feel*

***Nell:** I would probably laugh at him and say 'do you think I'm going crazy'*

This sentiment was echoed by some participants from the help-seeking category:

***Sue:** how do you think you would feel or on a future occasion if your GP suggested psychological therapies*

***Cath:** ... um ... I'd probably [laughs] shy away from it but .. if I was feeling really bad then I'm .. and I thought it would help then I would probably .. you know agree to it um .. I think my main concern would be um 'does that mean I'm mentally ill', again you know, the stigma that .. they talk about it here a lot [workplace], labelling people it's not right to label people but we do, we do that and I would probably .. but I think if I thought it would help me then .. yes I would, I would go along with it*

Patrick's example shows fears around referral to a *psychiatrist* in particular; he mentioned this whilst discussing his experience, and had not yet been asked about how he might feel if referred to psychological therapy. Hence, his use of

the term psychiatrist differs to the above discussion about referral to psychological therapies; however, his reaction is similar to those above and is therefore potentially salient:

Patrick: I think a lot of people when they say 'we'll refer you to a psychiatrist' or something like that then .. you think 'well I'm not mad, I'm not crazy I'm not going crazy' ... and the word 'psychiatrist' it .. it puts the fear into you, you think 'well I must be losing my mind or why would they say that' you know .. and it's .. I think it's got to be approached in a different manner I think you know to stop people being frightened of that .. you know because I don't think this ... in the light of day .. if somebody could come and knock on my door and say 'oh .. doctor so and so sent me round to have a chat to you I'm so and so psychiatrist' .. I would be shaking .. I would be terrified because thinking .. 'well why has he come .. why . why somebody like that's come'

Patrick's fear of being referred to a psychiatrist mirrors the fear mentioned by other participants in relation to referral to psychological therapies. Fears around referral to some form of therapy were not present amongst all participants. The expressed positivity around counselling, compared to the negativity expressed around psychological therapies (and in the case of Patrick, discussion of a psychiatrist), might result specifically from the difference in terminology, with 'counselling' being viewed as less stigmatising than 'psychological therapy'. What is pertinent to note is that at the mention of psychological therapies, some participants felt significantly fearful of the implications – that a referral would imply doubt about their sanity. This fear was not expressed in relation to 'counselling'. In relation to treatments that participants thought were available, counselling and medication were the main treatments that were suggested by participants, although referral to a psychiatrist or to a hospital were also suggested. 'Referral to psychological therapy' was introduced as a question to participants that was asked after discussion around treatment, and provides an explanation as to why the term was present in interviews (in addition to the term 'counselling' which was offered by participants).

What the lay participants thought was available was also shaped by how they viewed the *delivery* of treatment. I have already mentioned that participants viewed GPs as *gatekeepers* to services; participants also expressed concern around the availability of help, once referred. In particular, concern was expressed at a likely wait for any referral to counselling. Participants suggested that a wait rendered any referral likely to be pointless, as their problems may have been resolved by the time their appointment was due. Sarah, who was able to access counselling through her work, said:

Sarah: I think for a lot of people I think cost is an issue definitely

Sue: yeah that makes sense especially because .. you went privately and your work paid, for someone else they might not have that

Sarah: or the other thing as well you think .. if I'd thought well I'll go to the doctor and the doctor says 'well I suggest you see a counsellor' how long am I going to wait? Six months? Maybe longer? 'Cause there's not a huge amount of them ... you know if you're talking about NHS, well you almost think well why bother

Sue: hmmm because your problems are now aren't they

Sarah: yeah ... I think if somebody had said to me right Sarah I really think you need to see a counsellor that's a really good idea .. right yes, we'll make an appointment it'll be eight months, six months, I'd have said 'no, forget it ... just don't bother' ...

Sadie's experience is that she would like counselling following a very bad ending to a relationship eight years ago, after which she has felt unable to enter into another relationship. As a single parent she has been unable to afford private counselling, and does not believe counselling to be accessible in a way that is useful to her (*i.e.* immediate and free to access). She assumes that counselling takes place at a hospital, based upon her experience of hospital treatment for chronic health problems:

Sadie: I do believe that the whole counselling thing I think there should be more available or it should be more accessible then

Sue: so what for you would make it more accessible

Sadie: to even come like this to a community centre to even say 'oh we've got um' you know or even go to a drop in centre or citizen's advice bureau or somewhere like that do you know where they've got a counsellor, if you wanted to make an appointment and go and speak to them, I think something like that would be really good, so you don't have to go via your doctor and you don't have to then wait to go and see them at the hospital, do you know what I mean that sort of thing

Sue: mm mm ..so it would be kind of having them nearer by

Sadie: yeah definitely

Sue: or um .. without having to go to the doctor

Sadie: doctor yeah, and then wait months for hospital 'cause I know what hospitals are like .. you're waiting ages for an appointment I know I am anyway, so yeah I think that would be good if they was more accessible 'cause I don't think they are at all

Sue: and you did say earlier that you have to pay for them and like when you made enquiries [hear: 'when I made enquiries before yeah'] and that stops um

Sadie: a lot of people yeah especially single parents like me anyway yeah definitely I haven't got much money anyway, sort of, you know it's either that or buy your kid new school shoes well you buy your kid school shoes do you see what I mean you aren't ... being – when you are a mum you sort of push yourself to the back anyway with the kids, I need a coat and the kids need a coat well you get the kids a coat sort of thing do you know what I mean

Sue: yeah yeah .. yeah .. um ... so .. so kind of like having to go through the doctor is a bit of a hurdle [hear 'yeah'] yeah ok

Sadie: I think it would just be the wait as well, 'cause I don't.. could honestly imagine it would be a wait on the NHS to go and see a counsellor for free .. I think it would definitely be a wait [...] I can't imagine it to be 'oh you're right ok well you can go next Wednesday then' do you know what I mean it wouldn't be like that and I think by the time you'd actually gone got your appointment you'd probably feel a bit better anyway [laughs]

Sue: [laughs] yeah

Sadie: that's what it's like at the hospital with me .. feel really ill and by the time I get my appointment I'm better anyway so what's the point

In this excerpt Sadie suggests that she expects to have to wait a long time for any referral to materialise, and that this would render the referral pointless. She would prefer something more accessible in terms of located within the community and without the need to go via a GP. She had also previously expressed frustration at the cost of private counselling; when she had looked into the possibility for herself, she found it too expensive for someone of her means, as a single mum who does not work. Dennis expresses a similar frustration at the likelihood of having to wait for help via a referral, though in his example he suggests that the time delay leaves a person vulnerable to deteriorating (as was the case with his mother's delayed diagnosis of Alzheimer's):

Dennis: the GP, whether it be the GP social worker whatever .. should be able to provide you with that information [diagnostic and referral] like that [clicks fingers], it's what they're there for .. all the doctor will do is 'well I'll refer you to a colleague' that's in six months, um if you go private you can see him tomorrow.. [exhales] well not a lot of people have got the money

Sue: mm, yeah, that's very true

Dennis: so, the guy in the street's gotta wait six months or ... three months or whatever and in that three months they've gone downhill and it's very frustrating, I would like to see a vast improvement ... vast ..

So whilst attitudes to counselling are generally positive, there are concerns around perceived access, cost (of private counselling as an alternative) and waiting times that may deter some people from consulting their GP initially. This viewpoint was also expressed by Kara, who did seek help recently and was able to access private counselling through her own workplace instead of waiting for a referral via the NHS:

Sue: when you were referred to counselling how did that feel

Kara: I felt like it was a breakthrough to be quite honest with you .. when it came to the NHS one she was like 'oh it could be a month' I was like 'oohhh' [expresses uncertainty] and then when Angela rang me from here [workplace] and said you've got an appointment on Friday ...

In Kara's example, she had not sought counselling through her workplace as she hadn't perceived a 'problem' that required it; however, once a referral to counselling was received, to which she was receptive, the time delay of a month was perceived as off-putting and her ability to access counselling through work within one week led her to select that option instead. So, whilst individuals do view counselling in a positive light, this is then tempered by a perception that there would be a significant delay that would render it somewhat pointless. Expectations of delay do not necessarily bear relation to the reality of referral, but nonetheless there is an expectation of delay that may present a barrier to viewing this as a viable option.

Discussion

The findings in this section reflect much that was already known in relation to attitudes towards medication; it is viewed in a negative light (Prior *et al.* 2003, Pill *et al.* 2001, Priest *et al.* 1996) in relation to mental health, and indeed Williams and Calnan (1996) have found this in relation to physical health as well. As mentioned in the literature review, views around counselling have been found to be positive. The data provides new insight into what people expressed as fear around referral to psychological therapies; specifically, where participants responded with something akin to 'does that mean I'm mad?', the terminology of 'psychological therapies' in particular evokes a sense of concern amongst participants that was not voiced when discussing counselling. This was noticed amongst older participants in particular. Stigma is oft cited as a factor that inhibits help-seeking, and the stigma associated with referral to psychological therapy – specifically, the connotation that an individual's sanity is being questioned – is useful to note when considering the terminology used; the term 'counselling' was not associated with such stigma. The name of the IAPT programme – Improving Access to Psychological Therapies – which is

specifically intended to help people with common mental health disorders, may itself be increasing potential stigma for people who receive a referral.

In relation to beliefs about accessibility of counselling (specifically, a perceived time delay), participants' concerns pose a potential barrier to seeking (or accepting) help from their GP. As discussed in the literature review, Pill *et al.* (2001) point out that individual's evaluation of services may prove to be well-founded; repeating their pertinent citation here, they argue:

the reluctance of people to see their problems as requiring medical intervention has to be distinguished from their capacity to evaluate the services on offer. (Pill *et al.* 2001, p.217)

In Pill *et al.*'s study quoted above, participants' perception of services was that GPs had insufficient time to address personal problems, that GPs may not be tolerant of presentations of emotional distress, and that GPs may only be able to prescribe medication (Pill *et al.* 2001). Whilst the service provision context is different to that in which their study was written (*i.e.* the accessibility of psychological therapies has significantly increased since 2001), views around the delivery of such services present a barrier. Therefore, reluctance to seek care may also reflect an expectation that care will not be *delivered* in a timely fashion, and this is separate to any perceived suitability of a person's problems to therapeutic help. This was the most significant difficulty that was expressed by participants in relation to delivery of care, although short consultation times were also referred to (as found by Brown *et al.* (2011)).

When participants discussed the role of GPs in providing advice and signposting, there was an expectation that GPs provide guidance as to whether a person's problems are medical *or not*. Whilst this may seem trivial to point out, participants discussed the difficulties in knowing whether a problem was 'real' or not, and discussed negotiating different cues accordingly; this was pertinent to the discussions in chapters 4 and 5. What is important to note here, is that if in doubt, participants may consult their GP so that a *professional* opinion is given, confirming whether a problem exists and whether it is significant; it is the role of GPs to confirm whether a problem is within the remit of medicine. Participants are potentially open to *non-medical*

explanations for their distress as well as medical. Literature points towards a perception amongst GPs that individuals seek a quick fix (Shaw and Woodward 2004, Chew-Graham *et al.* 2000), and as mentioned in the literature review, GPs have a desire to alleviate individuals' suffering (Conrad 2007, Chew-Graham *et al.* 2000). However, this does point towards a potential mismatch between what individuals expect GPs to do (confirm if a problem is medical) and what GPs think individuals would like (receive some form of medical care). There is therefore the potential that individuals' distress is being responded to in more medicalised terms than might be preferred or accepted; this complements Williams and Calnan's (1996) argument that there is a mismatch between patient views of GPs overprescribing, and GPs' beliefs that patients want medication. As previous literature indicates, there is a perception that GPs are quick to medicate (and indeed this was expressed by participants in this study). It may be that this mismatch in expectations between the two groups, exemplified in what participants viewed as GP's primary role of *diagnosis* (*i.e.* confirmation whether their problem is within the remit of medicine *or not*), underlies why GPs are perceived as offering medication unnecessarily; this is most likely the case where individuals perceive the causes of distress as social. This could be a contributing factor to increased medicalisation of distress, that is taking part when GPs offer a diagnosis (as mentioned above), and not necessarily before then. I will address an alternative form of help in which individuals have expressed an interest, below.

What would both groups *like* to receive from their GP, if different?

It is important to consider what participants from each group *would like* to receive via their GP, if this differs to what has already been discussed in this chapter. This is with the intention of considering whether there are areas of incongruence between what individuals would like, and what is available, as this holds potential for useful practice recommendations. This will be done in two ways: firstly, I will examine what help-seekers said they *would have liked* (if this was expressed); secondly, I will examine what lay participants thought to be particularly helpful in ameliorating distress, if this has not already been addressed elsewhere. In particular, any areas of overlap between these two groups (that is, help-seekers and lay participants) should provide useful insight.

For those help-seekers who were happy with their experience (notably Cath and Kara), there was nothing else that they would have preferred from their GP; they had not known whether help would be available, and were happy with what was offered. Kara did, however, express relief when she was able to begin counselling immediately through her work rather than wait for the counselling via her GP that would likely commence after a month. In addition, Dylan did not want or expect any particular treatment as he knows nothing about the topic of mental health, and is happy that he has been supported thus far. It is therefore to be expected, to some extent, that those who have no expectations of treatment are unlikely to be disappointed at not being given a particular response; there was nothing they specifically wanted instead, nor expectations against which they were disappointed. Tanya and Anna both wanted to receive a referral to further therapy and both received this.

Three of the help-seekers specified a wish for a different response. Patrick was happy with the help that his GP provided (*i.e.* after giving him Valium and assessing his condition she was able to confirm he wasn't having a heart attack) but would like an additional form of help that he does not expect his GP to provide. Antonio and Sally Anne were both disappointed with the help they received, and wished for something different. There is a similarity between what Antonio and Patrick would have liked, and that is some kind of access to a group where they can meet others who might have had similar experiences. Antonio specifically hoped his GP might refer him to some kind of group therapy, or self-help group, where he might meet others in the same situation. He was disappointed when this did not happen; he did not specify that he asked for a referral, just that it was not offered. Whilst he felt that his GP was sympathetic, he wished to have some practical coping advice on how to deal with his grief and the tension that he feels as a result of it, and this he hoped to access by meeting others who were coping in similar circumstances. In addition he feels constrained by the short time allowed for consultation:

Antonio: in that case when my mum died, first of all she made me feel like she understood my feelings, like 'I know how you feel' and so on, like made me feel at least comfortable to talk about my problem, how I'm feeling and so on and so on ... of course she said that .. it was not time to

give some medicines for blood pressure or headaches, but to do some more activity and so on .. I felt a little bit uncomfortable because my time in there was 10 minutes, when you go to the practice always 10 minutes, 10 minutes, no more than 10 minutes, so I felt I wanted to talk more but I had no chance .. I would like if possible to be in touch with people with the same experience, in other situations when I feel stressed, but there's no chance for this, so it seems like you feel you're there alone with your problem ..[laughs] 'go and sort it out by yourself, because we cannot do so much' .. that's my problem [...] I would like ... that .. if you go for any related reason... to a GP .. not to be forced to express your problems in 5 or 10 minutes

When asked what type of help he would specifically like he reiterated the above, stressing that he wants to be able to meet others with a similar experience so that they understand him and he feels less alone; this would also help him access practical coping advice that deal with his concerns about his tension levels:

***Antonio:** first of all I would like someone [GP] that understands, that realises how I feel .. so it's a little bit .. she's a little bit supportive of my feelings.. and then to be in touch with someone that maybe has the same experience .. so that I realise that I am not alone and then .. to sort it out because .. it's easy to talk but if you don't know how to sort things out you just get stressed ...*

During participant validation, in which Antonio took part, he was surprised to hear that in the event of depression, his GP is potentially able to refer patients to counselling or other form of therapy. After discussing this possibility (about which I was asked more), he then said that given the opportunity between group therapy and individual counselling, he would prefer individual counselling because it would be taking place in English (his second language) and he might not be able to take part in a group situation as actively as one to one. His desire for some form of group therapy that was expressed in his first

interview was therefore voiced partly out of a lack of awareness of any other options; however, the preferences that he expressed initially remain pertinent.

Antonio voiced similar feelings to Patrick (whose preferences will be illustrated below) about the importance of meeting someone who has shared an experience, so that he doesn't 'feel alone'. He also places importance on 'sorting it out', that is, finding out from others how to deal with his problems on a practical level (*i.e.* to be given advice on how to cope), such as how to combat his grief or his inability to relax, a sentiment that Patrick shared. Patrick was satisfied with his GP's response; his panic attack abated once he knew he wasn't having a heart attack, and he was able to go home. He does however provide a detailed description of what kind of help he would find particularly useful, and that would help ease his anxiety in a meaningful way. Patrick would specifically like the opportunity to meet other people who may be experiencing similar to himself, or to have the opportunity to talk to someone in a context that is not constrained in the same way that GP consultations are:

***Patrick:** I know we all die .. there's nothing so certain as that but it's .. I think when you get older you can't explain to a doctor a doctor don't .. they haven't got the time to listen to you to say like ..I am frightened of the illness I've got because I know the con...[consequences] and what made it worse .. I was .. got an appointment to cardiac clinic [...] and I went to the cardiac clinic and the nurse, she was a nurse specialist in fibrillation episodes that people have .. and she says 'you're at very high risk of a stroke and heart attack' [...] I tried to explain to the doctor I got this panic this fear then, fear of dropping down dead anywhere and it .. although you try to put it out your mind, you completely try to blinker it, it raises its ugly head when suddenly you take your blood pressure one day and 'oh that's gone a bit high' .. for no reason .. you know and .. it's probably I'm leading myself into a trap that probably myself .. with linking what she said and what could happen .. and what I'm .. thinking you know to myself 'how can I avert it what can I do' you know 'who can I turn to' um [...] it's that.. fear .. it's the biggest fear when you get older it must happen to a lot of people if they're on their own [...] as soon as I*

get .. if I get that panic.. it's like your head's gonna burst you're .. you're in a globe and you don't think there's any way out you know .. there's no way out and you're taking your pulse and the more you're doing that the more you're working yourself up into a position where you can't control it .. you know what I mean you can't control your um .. the events that's happening .. all I'm doing is putting fuel in a way .. to the anxiety and that's what it purely builds up you see and it builds up into .. like the top of a hill and then you come tumbling down .. you know and you think .. who do I turn to .. you know I have had a word with the doctor and that .. but they're not in a position to say 'oh sit down and let's have a good hour's talk' and all that because they've got too much to do [laughs] too many patients to see ..

He doesn't feel as though he can talk to his doctor about his fear of his condition and of suddenly dying, because of practical constraints upon his GP's time. He would like the opportunity to meet other people, and to engage in social activities where he could both combat loneliness and also find out how others might deal with his particular problems; he would like the opportunity to be able to *relate* to other people and benefit from their experience:

Sue: *well you said that you don't see counselling as being .. useful in this way .. can you think of anything that for you would be useful so any form of help .. it doesn't need to be any kind of medical help it could be any .. what would you particularly like*

Patrick: *well I think a lot more in these community centres where you meet up... have a proper chat a game of dominoes and that [...] where you can go and meet together and get a chinwag and .. and I think that's where the benefits would come .. a lot more you know than just counselling .. because you are meeting people .. I'm not saying people that's got the same illness as yourself and that but .. you're not isolated [...] I think the helps got to be in the community, that's where it should be .. it's no good going to a doctor and going 'oh today I feel depressed doctor, I feel fed up' 'cause they haven't got the time, you don't wanna be wasting their time, but you could probably go to some community*

centre and feel a lot better once you're amongst people ... and I think that's where .. in the end .. it'd do more benefit .. it'd be more beneficial [...]

***Sue:** so you would see kind of like a regular social support network would be ideal for you perhaps.. I don't want to put words into your mouth by saying ideal but you know that would be something you'd like*

***Patrick:** yeah, that's what I've tried to explain ... that's better than all the medicine in the world really .. you know .. if you can just talk to somebody like I'm talking to you .. and you feel a lot better ... you've got it off your chest, and that person might be able to say well, say so and so, and what they've said they've eased your mind ... and there's a big difference .. that's where the massive difference is it's not the tablets ..the tablets block things out ..but things **rise again** .. it's being able to relate to a person .. and talk to that person, and that person could talk to you, listen to you and talk to you, and I think that's the biggest thing, and you can't go to the GP and demand that, I'm not saying it would be right but in an ideal world it would be right .. [emphasis in participant's speech]*

Patrick sees value in meeting other people who had shared experiences, and that this is better than counselling, which involves doing all the talking and not hearing about the other person's experience:

***Patrick:** ...if you can get the right people, the right people I mean if they'd been through .. I would put it in a nutshell ...if somebody like myself had been in that experience and I was clever enough to go to meet people to talk to them like I'm talking to you over what experience I'd had with mental health problems .. anxiety panic attacks depression .. that sort of person would definitely help, would be a massive stepping stone for somebody ... they've been through it they could say 'yeah well I've been through that' you're telling me 'yeah I've done that, I felt like that' and you just think to yourself 'well I'm not on my own' .. you know, 'I'm not a freak', you know it happens to other people it happens in real life to somebody else and I think that's where .. where that sort of counselling would go a long way .. 'cause it's the experience .. you could*

have a textbook or a medical book and what it's wrote in there .. if you're telling me what you're seeing down [on paper] and saying 'well it says in this book this is what you've got to do and all that' it wouldn't mean the same .. but if you told me that you'd been through that experience .. then that would help me more because it's a different approach you know .. I know then .. 'well yeah I'm not on my own' but from a book .. it says in this book you've got to do this, you've got to do that, you've got to see somebody you've got to say this to them .. that does not bring you on a proper level field .. it's pointing you in the wrong direction ..

Meeting others and sharing experiences is about more than just receiving advice from people about how to cope, but *relating* to others would also help reduce a sense of isolation and of being a 'freak'. He would be comforted to find out that he shares this experience with others, and to find out how they have dealt with difficult feelings and experiences. He contrasts this to receiving advice from a professional who has not had the same experience as him, and so is applying their learning (but not experience) to his situation.

Whilst Debbie was not recruited after a particular help-seeking episode, she nonetheless shares her feelings about what type of help she would like to receive. Whilst talking about the 'quick fix' of antidepressants mentioned above, she also mentions the benefit of meeting others with similar problems:

Debbie: *...you know you do want that quick fix .. but again I mean would it be better if they could, if there was some other way without just going straight onto the antidepressants I don't know .. bit difficult .. but that is what you want initially*

Sue: *hmm, just to start feeling better, some of the pain taken away*

Debbie: *yeah, yeah .. perhaps if they did that to begin with, and then sort of like you could start going to some classes on actually how to deal with panic attacks, what's happening when you do .. what they do know of it, if they could have classes of people that do suffer with panic attacks and things and say 'oh, would you like to attend' .. like the AA for alcoholics you know 'cause that helps, that really helps, knowing people that are suffering with the same thing as you .. because you do, you tend to think*

'cause you're in your own .. you live in your own little world don't we .. we all do you know, you think it's just you .. but then if you had classes they'd help each other

Again, Debbie refers to meeting others who are experiencing something similar so that she can realise she's not on her own, and also to learn practical ways of dealing with her depression and/or panic attacks. In chapter 4, I discussed the views of Anita and Julia from the lay group, who both place significance in meeting people who have shared similar experiences. This preference for 'social' support therefore has salience as a potential alternative for individuals who might not be receptive to medication or to psychological therapies.

Sally Anne's experience does not feed into the above desire for contact with others; rather, she would prefer to have the autonomy to take Valium on occasions when she is emotionally fragile, as she had been doing previous to a recent appointment. Sally Anne specifically wanted to be able to continue using Valium as she felt necessary, and not to engage in counselling. This is likely to feed into a larger theme that is prominent in her life at present – that of continued medical investigations into physical health problems that she is having. She does not wish to continue having these medical investigations, as she feels that there is little point in ascertaining the details of problems that are to do with her 'engine running out' (Sally Anne), that is to say, growing older and more frail. The investigations have so far proved fruitless, and yet have taken up much time and effort; she would rather enjoy the time that she has. She views her frustrating and somewhat unwanted medical investigations in a similar way to her counselling, and would prefer to carry on in her own way and simply learn to live with it:

***Sally Anne:** I felt that you know, I would have been better off, living in my own little fairy world, and just taking the Valium when I thought fit .. or when I thought necessary .. but I wasn't allowed*

She is aware of the potential for addiction and presumes this is why she was not allowed it, even though she states that she only used it on occasion and upon the advice of a different GP. Her more recent GP prescribed her 'happy

pills' which she doesn't feel do anything: 'I might as well have been taking aspirin' (Sally Anne), and her GP has asked her to attend counselling. She began attending counselling but did not find that it suited her and disagrees with the need to keep reliving her experience. She also found it difficult to address her issues with a counsellor who was much younger than herself (around 24 years old). She does not believe the counselling process works; from her point of view it is creating more pain, because she has to relive the trauma of her fracas again and again when she would rather try and forget about it and carry on her normal activities. In addition, her previous counsellor left the counselling service and so she will begin with a new counsellor in the near future:

Sally Anne: you see what I can't understand or .. probably it's a generation thing again, I don't know it's 2010 .. whatever's happened to anyone in life .. including myself, whatever's happened, living it out and keep repeatingly and repeatingly and repeatingly talking about it .. you know it's not going to help and writing it down's not going to help, 'cause all I can see at the end of the day I want to forget it, I want to get on I want to move on, but repeatedly asked to write it down and go through it and go through it, to me that's not helping me to forget, I don't forget it, but you put it in a little cupboard and you shut the door .. I mean you know periodically you might open that door or somebody else'll open it and then you go through that whole experience and then the nightmares start again and everything else and um ... and I can't understand it where you know .. a bottle of Valium would have done a .. she probably thought I were gonna take the whole lot but you know that's what it stemmed from so and I .. I shall go to a counsellor again next week and she'll be saying 'now what's the problem?' and you think 'here we go again' ... I mean you know when you knock somebody down in the road and you repair the leg, you don't say to them 'come on I'm gonna knock you down again' ... I'll see you a week on Wednesday and I'll knock you down again and you can suffer the same pain [laughs] ... and with them it's a physical pain with you it's a mental pain, not mental as mental but it's the distraught and the distress it causes you and

everything else .. you know just put it in that little cupboard and shut the door and you know.. every now and again you can open it uh .. but don't say to the man that's knocked you down 'I'll meet you a week on Wednesday, a week on Friday you can do it again.. it'll make you feel better' [...] I mean it might help some people but that's my own opinion, don't keep reminding me what's gone on, you know don't keep, like I said you know, don't keep running over the man with the broken leg ..

Sally Anne has had the autonomy of monitoring her own distress taken away from her, and is instead attending counselling that she does not want to attend, on the instruction of her GP. She would much rather live with her problems and adjust to them, than continue with treatments that she feels are inhibiting her current quality of life and may ultimately prove fruitless; this is likely exacerbated by her continuing medical investigations that she is also having to undergo.

Discussion

What can be seen from these examples is that for some participants, they place great value in meeting other people with whom they might share similar experiences. This holds the potential to reduce a sense of isolation, *relate* to others and gain access to a range of practical coping skills. The benefits of meeting others in similar situations was viewed as very important by some, yet this was not offered to any of the help-seeking participants despite its salience to the model of stepped care (NICE 2011a) that is applicable to common mental health disorders. What is interesting to consider, therefore, is *why* referrals to community or self-help groups might not be given. In research relating to the prevalence of social problems in primary care, Popay *et al.* (2007a, 2007b) discovered that despite GPs' beliefs that social problems underlay a significant proportion of their patients' health and mental health problems, GPs felt more comfortable referring patients to counselling services than to welfare support services (or similar). They found that GPs frequently do not have up to date knowledge about local services, and that this is partly due to the transient nature of such local resources (2007a). The services reported in Popay *et al.*'s study were mostly state-funded 'welfare'

organisations such as housing, Citizens Advice Bureaus and job centres, however they did also include community groups. Whilst it is unclear the extent to which ‘community groups’ in Popay *et al*’s study might overlap with ‘support groups’ that are mentioned in stepped care, the issue of up-to-date information available to GPs is one that is both highlighted as problematic in their study, and also essential to the successful implementation of this element of stepped care. As mentioned in the first section, two interviews were carried out with GPs; during one interview (after the theme of referral to community groups had been raised in participant interviews), I asked the GP (Katherine) whether they had this kind of information, and whether it might be useful. Her response was that they did not have such information, and that it would indeed be useful; the only referral information Katherine feels she has available is to secondary care. This is in conjunction with the option of medication; as illustrated in the first section, Katherine does not perceive a significant demand for either of these responses. There may therefore be some disparity between the bodies of resources that individuals expect a doctor to be able to draw from, and the reality of what GPs themselves might feel able and compelled to draw from. There is some expectation amongst participants (and some desire) that GPs will have access to, and knowledge of, a range of different types of referral including to community and/or self-help groups as mentioned above. This disparity in expectations might potentially feed into individuals’ distress being responded to in a way that is more medicalised than they might wish (or might be receptive to). Indeed, findings from Bristow *et al.* (2011) indicate a similar rejection of a solely biomedical response, and a potential desire for third sector or community help. Whilst this finding (within this study) is in itself not wholly original (it has been found by Bristow *et al.* (2011) in relation to hard-to-reach groups), it is worth noting that *this* study is not comprised solely of people from hard to reach groups, nor were they recruited via community groups, a factor that in Bristow *et al*’s (2011) study rendered the finding potentially representative of their recruitment methods. This study therefore supports the relevance of their findings to a wider demography, and also supports the idea that their finding was not necessarily an artefact of their method. This study therefore provides a recommendation to improve the availability of community, self-help and support group information that is

available to GPs, and to stress the importance of offering such referrals to patients, in line with stepped care. Bristow *et al.* also support such a recommendation.

To counterbalance the above discussion about the importance of community and/or self-help and support groups, some participants expressed great satisfaction with the help they received and were pleased to be referred to counselling and to receive medication. Help-seeking within primary care is heterogeneous and requires a broad range of potential resources to be accessible.

In the case of Sally Anne, who wished to have the autonomy to deal with her 'difficult days' in her own way through occasional use of Valium, and to accept her problems rather than attempt to ameliorate them through counselling (a process that she doubted worked and she found emotionally painful), there is less potential for service recommendations that might be useful.

Conclusion

It is important to reiterate that help-seekers are a heterogeneous group of people, and it is not possible to define *a* set of expectations that might be held around treatment, or *a* set of wishes that help-seekers have. Indeed, the same can be said of the lay group, and there was great variety amongst participants in terms of what they perceived to be helpful in ameliorating common mental health problems. There is a universal expectation that GPs have the ability to diagnose and refer to appropriate services, thus playing the role of gatekeeper and also reassuring patients as to whether their problems are indeed amenable to medical help. Therefore, when considering the expectations of individuals, the findings apply to *groups* of individuals within the study; there are no overarching expectations except the very broad expectation of diagnosis and appropriate referral.

The data indicates that the process of medicalisation (that is, problems coming to be defined in medical terms and more particularly, receiving a medical response) is cemented when a GP offers a medical response, and not necessarily before then; this feeds into a discussion of medicalisation more broadly, and provides a contrast to the notion that patients are driving

medicalisation (Conrad 2007). GPs may perceive a *need* or *desire* for help in the form of medicalisation of distress (as suggested by Shaw and Woodward (2004) and Chew-Graham *et al.* (2000)) when individuals are simply trying to understand their distress and ascertain whether medicine is *appropriate*. In this scenario it is likely that medical help is being offered when individuals may be willing to accept (or indeed prefer) an alternative response. This has potential consequences for the course of an individual's distress (that is, redefining an individual's distress through a medicalised lens, and increasing the potential for a medical pathway for help in the event of future distress), and also for the use of NHS resources in addressing problems that individuals may prefer to address within community or self-help groups. There is some difference between patient understanding of the scope of advice that a GP is able to give (and refer to), and the realities of referrals in a GP setting, that may culminate in increased medicalisation of distress. In particular, participants in the lay group describe mental health problems as resulting from mainly social causes (as discussed in chapter 4). A strong preference for social support is also evident, and whilst there is perceived benefit in medication and counselling (although individuals appeared to shy away from medication for themselves), some individuals stressed the importance of meeting others and of not feeling alone in one's situation. This is therefore a potentially useful form of referral to consider in terms of providing a response to help-seekers; individuals may wish to meet others in the same situation, in order to understand how other people with similar problems learned to cope. Whilst there is the potential for this within stepped care and referral to self-help and/or support groups, it does not appear to have been provided as an option to any of the participants in this study; work by Popay *et al.* (2007a, 2007b) provides insight into the difficulties that GPs face in maintaining up-to-date information of such groups, providing some explanation as to why such referrals might not take place. Thus, this forms the basis of a recommendation, that access to community, self-help and support groups be enabled by the provision of up-to-date information to GPs, and that the benefits of such referrals be stressed to GPs.

Feedback in relation to receiving a referral to psychological therapies was mixed. Some participants perceived potential benefit in having the opportunity to deal with their distress, but this may be accompanied by a fear

that in being referred to psychological therapies, there was the implication that they were 'mad'. This appeared less so when the term 'counselling' was used. Referral to individual therapy therefore has mixed implications. This provides additional support for the alternative of self-help and/or support groups, where individuals can meet others and find out they are not alone in having the problems that they have. This lends weight to the potential benefit of highlighting the use of referral to self-help or community groups as part of stepped care; referral to individual therapies may potentially frighten individuals. There is also a perception amongst participants that the delivery of services (specifically a referral, for example, to counselling) might not occur in a timely fashion, and this acts to deter individuals from considering this sort of help as a viable option.

The data shows that help-seekers' expectations cannot necessarily be viewed as drivers of action, as some participants held no specific expectations around care; medicalisation of distress, and purposive action is applicable only in certain cases, and in particular, amongst longer-term mental health service users. Rather, a more haphazard approach, as described by Pescosolido (1998) takes place. The idea of framing has been considered, and this has been found to be mostly applicable in the case of people who have a history of seeking help. For those who are newly seeking help, consulting a GP represents one of a number of different resources that were tried (including coping), and individuals may not expect medical help to be appropriate. As mentioned in the previous chapter, help-seeking frequently takes place based upon the interaction of specific events, including other people's intervention, rather than a case of 'rational' decision making. Whilst the notion of 'framing' may appropriately encompass the intervention of other people who offer advice to seek help (*i.e.* their advice may reflect the extent to which their own views are framed), it is not necessarily taking place in the individuals themselves. Thus, the findings in this chapter are congruent with the findings of the previous chapter – that help-seeking is not necessarily an individualised act (individualised being representative of deliberate action, or of expectations around care) – but rather is the outcome of a complex process that involves trial and error and may not actually reflect a wish for medical treatment.

The next chapter will summarise the findings from the study as a whole, the study's overall contribution to knowledge, and considers the data chapters as a unified whole.

Chapter 7

Conclusion: Viewing help-seeking within its wider context

This chapter provides a summary of the study's findings, in relation to each chapter and then tying together as a whole. Overall, the study shows the different ways in which help-seeking might reflect, or be shaped by, its context and argues the need for theoretical approaches to help-seeking to move away from purely individualised explanations. Help-seeking is inseparable from its context, although there is a tendency within the body of research to focus upon individual attributes and to view help-seeking as an individualised act. This thesis sheds light on the potential limitations of an individualised approach. It also sheds light on the complex processes that impact upon the medicalisation of an individual's distress. This chapter provides a summary of the different chapters and then summarises how they answer the research questions and unify to shed light on the *context of help-seeking*, and specific nuances that might hinder or enable it. I will also provide a brief reflection upon the study.

Summary of individual data chapters

Chapter 4

Chapter 4 shed light on the *nature* and *content* of lay understanding in relation to 'mental health'. The chapter highlighted the idiosyncratic, biographical, philosophical and fluid *nature* of lay understanding, that reflected previous findings and fed into a useful and timely caution that researchers should be wary of assuming that lay understanding can be used to *predict* behaviour. When considering the *content* of lay knowledge, different views were found that comprised notions of well-being, mental function (including *any* 'difference' relating to the brain), illness and vulnerability. Participants defined mental health problems with reference to problematic notions of 'normality', and discussed different ways in which measures of 'normal' and 'disordered' emotions and/or behaviour might be categorised and responded to. The data echo previous findings in relation to when individuals might perceive formal help to be necessary, and these thresholds relate to the ability to carry out their daily functions (for example to work, or look after children) and their

ability to ‘cope’, echoing the work of Zola (1973), Pill and Stott (1982) and Blaxter (1990). The salience of physical cues (such as inability to sleep or persistent headaches) is expressed as an important indicator to individuals that something is ‘wrong’, and individuals discussed different permutations around how such an identification might be made.

The most commonly perceived cause of mental health problems related to the social world, that is, aspects of a person’s life including their upbringing, traumatic events and ‘normal’ life problems such as relationship breakdown or financial worries. Participants also expressed the importance of social support, in terms of ‘practical advice’ as well as emotional support; ‘practical advice’ encompassed advice relating to the perceived *causes* of a person’s distress, such as relationship breakdown or financial worries. Practical advice was not only perceived as addressing the causes of a person’s distress, but was also something that participants felt they could provide that was within their ability to provide. Participants showed a tendency to focus upon the perceived causes of distress when seeking solutions, as opposed to necessarily viewing distress as pathological, underpinning the process of normalisation when attempting to respond to distress.

When considering participants’ lay understanding in relation to hypothesised help-seeking, there was a discernible relationship between what individuals perceived to be the nature of mental health problems and what might help them (*e.g.* beliefs about biological causes accompanied views around the benefits of consulting a GP and taking medication). Indeed, views were expressed that would entirely discount the use of GPs, for example a participant’s religious beliefs provided a more appropriate solution to any enduring distress. However, this relationship was viewed with caution, based upon the warnings of previous writers such as Blaxter (2010) and Bury (1997), and an understanding of the inherently *hypothetical* nature of any predictions made by participants who had not sought help for distress from their GP. This chapter did, however, provide useful insight into the lay knowledge that comprises the networks in which help-seeking decisions are made, and provided useful and original insight into the depth of lay understanding, and the reasons why individuals perceived benefit in *practical* advice. This chapter illuminated the context in which help-seeking advice might be given, and how

individuals might attempt to understand and define another person's distress without labelling or perceiving it to be within the remit of 'mental health' until other explanations (related to the social world) have failed.

Chapter 5

Chapter 5 provided insight into the help-seeking process from the perspective of recent help-seekers. Their stories provided valuable insight into the process of interpretation that may or may not take place relating to a person's distress; problems relating specifically to normalisation reiterate the salience of this concept to help-seeking research. The chapter went on to illustrate the importance of context to an individual's help-seeking process; individuals' wider networks played a role in certain examples where individuals struggled to perceive anything specific as being 'wrong'. For other participants the salience of other cues such as the occurrence of a crisis, an adverse event or fears around physical health, played an important role in bringing them into care suggesting an interplay between a person's help-seeking and their wider life that cannot readily be separated for the purposes of reducing help-seeking to unitary factors (such unitary factors include a person's *understanding* about mental health); help-seeking is an inherently contextual process. These findings reiterate (and extend) the salience of Freidson's lay referral networks (1970) to include other aspects of individuals' lives. The study therefore elucidated the relationship between lay understanding and help-seeking, by shedding light on the *additional* factors that played a pertinent role to the distressed participants in this study. This differs from the more 'rational' *hypothetical* help-seeking that was discussed in the previous chapter that is frequently referred to when theorising the relationship. Lay understanding remains important in helping to understand the context in which help-seeking advice – as well as 'practical advice' – is given, and also in shedding light on its *limited* (yet still present) role in help-seeking alongside these other factors.

The chapter also provided insight into specific nuances around coming into contact with some form of help, that reflect how distress is *more* or *less* likely to enter into formal care; this depended upon a person's wider network, and this includes presence in medical care not related to mental health, in

which participants may have had regular contact with healthcare professionals. Contact with a healthcare professional (related to *physical* health) renders distress potentially likely to be viewed through a medical lens, and this represented one original aspect of the study findings. The data also contributes to a growing understanding in the field relating to the contextual nature of help-seeking that is currently being forwarded by the Network Episode Model (NEM) (Pescosolido and Boyer 1999, Pescosolido 2011), and provides data from a unique perspective (that is, a qualitative interpretive UK-based study) to this approach.

This chapter provides insight into the difficulties associated with interpretation of a ‘problem’ for individuals whose distress is intimately associated with extremely distressing life circumstances. It goes on to show how the process of interpretation (and of accessing resources) was shaped by the individuals’ wider lives and networks, thus pointing towards the necessity to view help-seeking as an act that is not wholly individualised. Presence within a medical setting (for physical health problems) increases the likelihood of help being sought two-fold, in that distress is both more likely to be *present* (if seeking help for a significant health problem) and also more likely to be *observed* by a medical professional who advises seeking medical help.

Chapter 6

Chapter 6 explores the expectations of both groups. This chapter first considers whether deliberate or purposive action reflecting medicalisation of distress is an appropriate way of understanding help-seeking, and uses help-seekers’ expectations of care to do this. According to the data, purposive action is not an appropriate framework unless help-seekers have already experienced some form of previous care in relation to their mental health, in which case they seek further care with this in mind. For experienced help-seekers, their views have been ‘medicalised’ and they continue to view their distress through such a framework. For newer help-seekers, the seeking of help represents more a haphazard process that does not hold any specific expectations in relation to the relief of distress. Drawing upon the previous chapter’s findings that help-seeking is not necessarily an individualised act, the appropriateness of purposive action as an explanation is reduced, as participants’ actions were not

necessarily based upon the action of *individuals*, but rather the outcome of a chance sequence of events including the intervention of others. The findings of chapter 6 are therefore congruent with the findings of chapter 5.

The second half of the chapter addresses the content of individuals' expectations, and provides useful insight into an expressed desire for referral to groups (whether self-help, support or community groups) that individuals did not receive, despite the salience of this type of referral to the process of stepped care. This forms the basis of a policy recommendation that the availability of information about such resources should be improved for GPs. Lay participants perceived there to be a significant time delay between attending a GP consultation, and entering into any talking therapy (talking therapies encompassed the majority of referrals discussed). Such a time delay was perceived as a barrier to effective relief from distress, which was viewed as an immediate concern as opposed to something that could wait for a referral. Fear was also expressed relating to the possibility of referral to psychological therapies – that such a referral implied the individual was 'mad'; this fear was not present when discussing referral to counselling. In relation to terminology, there is therefore a difference between the two in the level of perceived stigma, with counselling being viewed more positively.

A discussion of medicalisation permeated the chapter, and the participants' data goes against current views that patients are driving medicalisation and *want* a medical response; rather, patients appear to seek professional advice as to whether medical help is *appropriate* (the subtext being that it *may not* be appropriate). Based upon research suggesting that GPs expect patients to *want* a medical response, there is a mismatch between what individuals *seek* and what GPs *provide*, that may culminate in increased medicalisation of distress *by GPs*. Where participants have already received help from their GP relating to distress, this is likely to shape future help-seeking.

This chapter considers the content of individuals' expectations around care, and how they align with (or do not align with) the provision of care through a GP. This provides insight into the extent to which expectations of care (when present) might reflect their healthcare context, but also where there is disparity between the two.

Viewing the data chapters as a whole

This thesis elucidates the process of help-seeking from three different perspectives: firstly, it considers lay understanding and help-seeking – what individuals perceive ‘mental health’ (and ‘mental health problems’) to mean, what might cause or ameliorate mental health problems and, importantly, when help-seeking might be appropriate in relation to psychological distress. Secondly, it sheds light on help-seeking from the perspective of help-seekers, and illuminates the extent to which help-seeking was an outcome of their context as opposed to an individualised act. This provides additional insight into the relationship between lay understanding and help-seeking – it shows its *limitations*. Chapter 5 provides insight into the other factors that shaped the help-seeking process *in addition to* lay understanding, pointing towards the need to view lay understanding as only one aspect of the help-seeking process (if at all). Thirdly, it shows how help-seeking (and from the perspective of the lay participants, *hypothetical* help-seeking) might interact with an institutional response. It considers participants’ expectations of services, locating help-seeking (and any associated expectations) within a specific healthcare context. When taken together, the chapters show the interaction between an individual and their context when experiencing distress. The findings of the study provide insight into specific nuances that feed into help-seeking outcomes, that help to provide some explanation as to why patterns within help-seeking statistics do not always reflect ‘need’. The chapters also shed light on the nuances of when individuals might view distress as something amenable to medical help, and when they might not, suggesting that medicalisation of distress is less readily done than some literature suggests (for example, the desire for a ‘quick fix’ that Chew Graham’s (2000) GPs discuss).

Recent research by Biddle *et al.* (2007) highlights the benefit of an interpretivist approach by illuminating the ‘cycle of avoidance’ (COA) that individuals displayed when interpreting their own distress. The COA sheds light on processes within the individual that continually push the threshold of what is considered ‘normal’ distress ever farther out, until a crisis occurs; this avoidance of acknowledging ‘real’ distress leads to delay in help-seeking until it is unavoidable. Biddle *et al.* contrast this interpretivist approach against a background of reductionist and deterministic accounts that fall short in

understanding *why* help seeking happens when it does (and why some individuals do not seek help despite the presence of disturbing inner experiences). They also contrast their approach with the work of Pescosolido, who over the last twenty years has provided insight into the role of networks in helping individuals to interpret their symptoms (as well as other factors affecting help-seeking and treatment compliance). These contrasting approaches provide insight into differing aspects of individual's lives, and how their illness careers might be shaped. The findings of this study fall somewhere between these two perspectives, that is to say, it engaged an interpretivist approach to study individuals' internal processes (as with Biddle *et al.* (2007)), yet culminated in understanding help-seeking as affected by a person's context and not just their interpretation of distress (or other internal processes). The study shows how individuals' help-seeking trajectories are affected by life events and the interpretation of those around them, as well as a failure of their own resources to contain their distress within tolerable levels (or to provide access to alternative forms of help). This then shows the complex process of interpretation that takes place within some individuals, but places this as only one factor that affects an overall help-seeking event. The relevance of this study's outcomes are most pertinent in understanding how the process of interpretation is affected by different factors pertaining to an individual's context, and in illuminating the important role that other members of a person's network might play in helping someone come to care (or not). This study provides insight into the diversity of help-seeking scenarios that culminate in help being given in primary care, and point towards the complex array of factors that feed into a person's illness behaviour; reductionist models that seek to account for help-seeking (and non-help-seeking) based on demographic factors are likely to mask complex processes that underlie help-seeking figures.

This thesis charts the findings of a project that explores how, when and why individuals might view psychological distress as something that might be amenable to medical help. What started out as an exploration into help-seeking, and whether help-seeking might be framed by beliefs around medical help in relation to distress, ended in greater understanding into how individuals might negotiate the potentially difficult area between experiencing distress, and seeking help for it. Whilst deeper understanding around lay knowledge helps to

provide insight into ‘thresholds’ of distress and triggers for seeking help (reaffirming the continued relevance of Zola’s (1973) early work), research into lay understanding can only shed light on *hypothetical* help-seeking; when compared with the reality of distressed help-seekers, lay knowledge informs only one aspect of help-seeking, and a person’s wider context (including the experience of distress, and their social networks) helps to elucidate how and why some people come into care when they do. This brought into play a broader range of contextual factors that affect help-seeking, as opposed to an individual’s interpretation and expectations alone. I began the study with an interest in how the contemporary context of mental health care provision might frame a person’s expectations, drawing upon literature that posits present-day members of the public as proto-professionalised (De Swaan 1990) and open to having their emotions viewed within a medical paradigm. However, the data pointed towards this as being less than clear-cut, and suggests that whilst language drawn from the professional field of mental health care might be used by members of the public, this does not indicate wholehearted agreement with treatment methods, nor with help from the medical field itself; medicalisation of distress is only partial. Where possible, individuals appear likely to attempt to resolve their problems without medical help, seeking help only when attempts to cope have proved unsuccessful. However, medicalisation of distress is increasingly likely if a person has contact with a medical professional, suggesting that Armstrong’s (1994) argument – that a person who is assessed by a clinician will be assessed within the framework of a specific paradigm (with corresponding treatment response) – may be applicable to distress that is observed by medical practitioners in a medical setting, during a consultation that is unrelated to mental health care provision. In these examples, distress is understood and responded to within a medical paradigm, and it is by being in contact with a medical professional that the notion of ‘candidacy’ (Dixon-Woods *et al.* 2005) in terms of mental health care is negotiated. Complex patterns in help-seeking that exist may be affected by this specific route to care that has previously been related to women’s increased help-seeking through attendance at consultations related to fertility (Hunt *et al.* 2009).

The overarching research questions for the study were:

According to the accounts of individuals, when and why do some people seek help from their GP when experiencing distress? And what role does lay understanding play in this?

Chapter 5 addresses some of the nuances into why help-seeking takes place when it does; it provides insight into the contextual nature of help-seeking, and reiterates the continuing importance of Zola's (1973) triggers, which place an individual's wider social life as salient to any help-seeking. The chapter also sheds light on the processes by which individuals who are attending medical care (related to their physical health) are particularly likely to seek help (or be advised to seek help) for emotional distress, and this is one of the study's original findings. In addition, it provides insight into the difficulties that individuals who are experiencing particularly distressing circumstances might face in viewing their distress as 'a problem'; normalisation is particularly likely at such a time. Therefore, the study sheds light on some of factors that hinder or help the interpretation of emotional distress as a mental health problem.

Chapters 4 and 5 shed light on the nature of lay understanding, and upon its limited role in the process of help-seeking; help-seeking is the outcome of a range of different factors, of which lay understanding is but one. Therefore, the relationship, which is the subject of much research, is most discernible when discussing *hypothetical* help-seeking, a factor that limits the applicability of such research to an actual help-seeking situation.

Chapter 6 provides insight into individuals' expectations of GP care in particular, and points towards a potential disparity between what individuals *expect* a GP to be able to provide, and the reality of service delivery. Individuals may not actually wish for a medical response, but rather would like confirmation of whether their problems are indeed 'medical', and the potential for signposting to resources that encompass a more 'social' approach to help (that is, self-help groups, group therapy or community groups). This therefore points towards a potential misunderstanding on the part of GPs who may expect patients to be asking for a medical response (Chew-Graham *et al.* 2000). In addition, whilst there is the potential for such a referral through stepped care, the realities of service provision may not be geared up towards such referrals.

Thus, whilst patients may indeed seek help (or, more appropriately, advice) from a GP, this does not necessarily mean that they are seeking a medical solution.

Original contribution to knowledge

The study provides an original contribution to knowledge in a number of nuanced ways, which contribute to increased understanding in this field:

- In relation to the content of lay understanding, the study provides a depth of insight amongst UK participants that has not been provided elsewhere. It shows preferences for care, and the processes through which individuals pass in relation to the interpretation of distress, that focus upon the *perceived causes* of distress until these options have been exhausted.
- The study points towards the processes by which individuals receiving care for significant and enduring health problems are, at once, simultaneously distressed by their circumstances and also have their distress witnessed by a medical professional who categorises it as amenable to medical help. It sheds light on the role of the ‘medical gaze’ in categorising distress as amenable to medical help.
- The study points towards an expectation on the part of some individuals that GPs are able to provide referral to a broader range of services than may be feasible within a GP consultation. It points towards the potential desire for referral to groups within the community, widening the salience of Bristow *et al*’s (2011) recommendations that were based upon a narrower demographic
- It highlights the *limitations* of the relationship between lay understanding and help-seeking, by illuminating other factors that significantly affect the seeking of care. The findings indicate that help-seeking should not be viewed as a wholly individualised act, and the study provides support for Pescosolido’s (2011) call towards taking into account the networks around an individual, support that is derived from a UK-based interpretivist study.

The theoretical contribution of this study is that it provides insight into the role of lay understanding in the process of help-seeking; it helps to understand the *limitations* of lay understanding in determining help-seeking, and that help-seeking *is not necessarily an individualised process* (thus, lay understanding, or any model that assumes purposive action on the part of an individual, may be inaccurate). I also illuminate lay understanding and how an individual's context *is* framing help-seeking; thus, I provide some refinement of how the relationship between the two is enacted. In addition, emergent themes have helped to shed light on contextual factors that significantly shape a person's likelihood of receipt of care, and points towards the need for a shift in focus from the unit of individual to one of a 'person in context'.

Reflection upon the study

This study began as a CASE studentship that was tasked with investigating help-seeking through lay understanding. Underlying such an approach was an expectation that lay understanding fed into help-seeking, reflecting much research that discusses such a relationship from the point of view of an individual's internal process *i.e.* that their understanding guides behaviour, and that the lay referral context shapes help-seeking decisions and advice. The study was designed to illuminate lay understanding and to consider how this might have shaped the stories of help-seekers; this was based upon the assumption that contextually-specific beliefs around the nature of distress (and associated help that is available through a GP) might drive individuals to seek resolution from a GP. What was found to be the case differed from the study's underlying expectations; lay understanding plays a *limited* role in help-seeking, and the stories of help-seekers provided insight into factors that were related to the individual's wider social world as also playing a role. This chimes with much research that discusses the contextual nature of help-seeking (from Zola (1973) onwards) and thus points towards an understanding of help-seeking that is less individualised than it is frequently assumed to be – certainly when compared to the body of research that seeks to uncover the relationship between lay understanding and help-seeking. By attempting to consider the relationship between lay understanding and help-seeking – two related yet distinct bodies of literature – the study design culminated in findings that

pertain to each of these as separate phenomena, as well as to their *relationship*. This therefore leads to range of findings that is relatively broad, that is to say, findings that range from the *content* of lay understanding, to the refinement of *theoretical approaches* towards help-seeking; this is somewhat inevitable when undertaking a study that seeks to investigate the relationship between concepts whose relationship may turn out to be more limited than expected. Nonetheless, useful insight is gained into both areas that can be translated into useful service recommendations as well as furthering the understanding of their relationship.

During the design stage of the study, there was an expectation that the research might lead to insight that reflected individuals' inner experiences, similar to the work of Biddle *et al.* (2007). The study therefore focused upon individuals' stories (and in the lay group, upon their views and experiences). However, whilst the data showed that individuals' interpretation was central to help-seeking, other factors also played a role and the process of interpretation was significantly shaped by a person's context and other events that were happening in their lives (that might be causing, or coinciding with their distress). The outcome was that the use of individual's stories led to insight into how for some participants the process of interpretation, and the associated help-seeking process, reflects the individual's inner experience *in tandem with* their wider context. This falls somewhere between the interpretivist work of Biddle *et al.* and the context-illuminating work of Pescosolido and Boyer (1999). However, because the study was designed to focus upon individual stories, as opposed to an analysis of their networks or social capital, the presence of 'context' within the study data is derived from the participants' stories alone. It does not reflect the context-illuminating detail that is available through other methods that are specifically geared towards examining context, for example Pescosolido (2011) advocates a mixed methods approach. This could be one potential avenue for further research.

The study's initial focus upon the processes internal to an individual, that arose from an understanding of the literature that pointed towards the importance of the *meanings* (to individuals) attached to illness, shaped its design, however the findings point towards the need for an understanding of help-seeking as contextual. For this reason, the literature review was expanded to highlight this more contextual approach, reflecting the iterative nature of the

study, and in acknowledgement of the fact that the findings have shaped the study's boundaries.

Reflection upon the role of the researcher (continued from chapter 2)

Having discussed my own status as a help-seeker in chapter 2, it is useful to now reflect upon similarities and differences between the study's findings, and my own personal experience. It is important to consider the extent to which my own experience may have shaped the analysis and findings, and to make the relevance of my own experience explicit. At the end of the first year of this study, during which the study design was addressed, I came across the work of Hunt *et al.* (2009), which made me recall my own experience as beginning with that one crucial ingredient, that of attending a routine appointment relating to contraception. At the time, whilst I found this interesting as a reflection upon my own case, I did not consider it likely to be relevant to the study as, perhaps naively, I assumed that help-seekers within the study would mostly be people deliberately attending a consultation relating to distress; in addition, my study was not aimed solely at females. Upon carrying out the fieldwork, I came to understand that some participants' seeking of help was contingent on their presence in medical care; not only was their seeking help contingent on this, but also their distress was directly related to their *physical* health problems, their reason for being within the medical setting. My own experience is useful confirmation of Hunt *et al.*'s (2009) findings, and has some similarity to this study's finding in relation to the importance of presence within a medical setting; however, whilst my own experience (and the work of Hunt *et al.*) and this study have similarities, there are pertinent differences. This study's finding relates to the experience of people who were experiencing incredibly distressing health-related problems; I am referring to the stories of Dylan, Anna and David (who was discussed in the methodology chapter). Their experiences differed to mine in that their health-related problems either caused their distress, or exacerbated it, and they were at once also within a medical setting. This differs to my own experience, in that mine was a chance attendance for an unrelated (and non-distressing) issue, whilst experiencing distress, as per the work described by Hunt *et al.* Whilst my experience is still *related* to this study's finding, it is not a parallel example, and there are

pertinent differences. This provides some reassurance that the study findings represent the experience of the participants, and not my own, however it is important to point out my own experience so that this is explicit.

Directions for further research

There are a number of potential areas for further research, and I briefly mentioned above the potential for a mixed methods approach that sheds greater light on an individual's networks, with those networks as a focus of analysis (for example through social network analysis or a focus on social capital). Deeper understanding of the role of specific networks – in the context of the present day – could shed useful light on pathways towards care that were first illuminated, for example, by Horwitz (1977).

Alternatively, one of the most interesting findings of this study is the process by which individuals who are receiving care for significant physical health problems, are at once distressed and under a medical gaze. This would be a useful direction for further research – to explore the different processes by which such referrals are made, and the extent to which such referrals might feed into skewed statistics. To what extent is the medical gaze extending into individuals' lives? This extends an argument drawn from Hunt *et al.* (2009), that women's increased presence in a medical setting related to contraception and child-rearing might partially account for their increased help-seeking. It would be a fruitful area for further research to consider the nuances by which presence within a medical setting (for matters relating to *physical* health) shapes the medicalisation of distress. This could also provide useful insight into the referral process, and suggest potential pathways towards specialised support (including non-medical, for example support groups) that may prove popular.

Having mentioned support groups above, another fruitful avenue for research would be to examine what referral preferences individuals might have when in receipt of advice or referral from a GP; this extends beyond those highlighted above whose receipt of care is contingent on already being within a medical setting. The importance of community support groups, self-help and/or group therapies has been highlighted in this study, and it would be useful to understand more about which types of referral are perceived as welcome, and

why. Whilst this study highlighted certain perceptions about the nature of psychological distress and the type of help individuals might want to receive, it would be useful to focus upon the types of support highlighted as the particular object of inquiry. Enhancing the referral process that takes place within a GP consultation holds great potential for increasing individuals' satisfaction with the outcome of their consultation; in addition, it holds the potential to increase engagement with treatment and/or support (in the case of non-medical help) and potentially to reduce the number of DNAs at psychological therapies (by signposting to an alternative, preferred option where applicable). There is great value in understanding more about the types of help to which distressed individuals might wish to be referred.

Summary

The findings depicted in this thesis are the outcome of a research journey whose pathway evolved throughout the process. In the above paragraphs, I have outlined aspects of the study's aim and design that reflected assumptions that were not borne out by the data; the findings were unexpected and provide useful insight of relevance to practitioners and academics alike. It is useful, therefore, to highlight the main findings of the study here, to reiterate their relevance to the wider field and point towards fruitful research in the future, alongside that which has already been outlined. The main findings of this thesis, of which academics and practitioners should take note, are as follows:

- That help-seeking, or attendance at a consultation in primary care does not necessarily reflect a desire for medical treatment (although it might)
- Individuals may be receptive to, and indeed desirable of, referral to support that does not treat their distress as a medical issue; individuals may wish to meet others in the same situation so that they can receive practical coping advice, as well as reassurance that they are not alone in having the problems they have.
- Lay understanding plays a limited role in the process of help-seeking; whilst assumptions around the nature and suitability of medical help may play a part in *some* help-seeking, much help-

seeking represents the failure of other resources to alleviate a person's distress

- Help-seeking is not necessarily deliberate, and some individuals who come to receive care do so as a result of their distress taking place within view of a medical gaze. For this reason, people who are in receipt of medical care relating to their *physical* health, who may have reason to be distressed, are particularly prone to having their distress medicalised.
- Help-seeking is not necessarily an individualised act, and a person's wider context plays an important role in the likelihood – and timing – of them coming into care.

These brief points are useful to note when considering the provision of care; they point towards less of a deliberate desire for medical help than is frequently believed. GPs in particular should bear in the mind the potential range of responses to which an individual might be receptive. As discussed earlier on in this thesis, once a specific pathway has proved useful for alleviating distress, it is likely to be used again in the future; there is therefore potential benefit in helping individuals – who may wish for advice, support and understanding – to receive signposting towards groups and/or community resources that can provide such help, alongside the resources that GPs already use. The directions for further research outlined above hold the potential for further enhancing the referral process, as well as understanding more about how individuals' contexts shape the receipt of care.

Appendix 1



Study leaflet

Study title: Help-seeking behaviour of people experiencing psychological distress

*We would like to invite you to take part in a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Here are some details about the study. **If you are interested in finding out more, then please return the ‘expression of interest form’ in the prepaid envelope provided, or telephone the research team on 0115 9515227 (ask for Sue Brown) or e-mail lqxsb5@nottingham.ac.uk, and we will give you more information about the project.***

Here are some things you should know about the study:

What is the purpose of this study?

This project will examine beliefs about mental health and mental illness, and whether these beliefs affect how people who are distressed (that is, experiencing psychological distress) seek help. The aim is to discover more about why certain paths are chosen (such as visiting a General Practitioner or ‘GP’) by some and not others. A lot is known about different patterns of help-seeking, such as differences between men and women, but not much is known about why these differences exist, and that is what this project will begin to examine. The starting point is to examine what the general public thinks about mental health and mental illness, and this is where you come in.

Why me?

Your address has been selected at random, alongside other addresses that fall within the boundaries of NHS Nottingham City. We are looking for people who fit the following criteria:

- they live within the boundaries of NHS Nottingham City (such as your address)

- they have never been to their GP in relation to psychological or emotional distress
- they are not a mental health professional or health care professional.
- They are 18 years of age or over

If you meet **all of the above** criteria, and are interested in taking part, then we would love to hear from you. You should read the rest of this leaflet before you decide.

*(If you do not meet the above criteria but are interested in taking part then please read the paragraph at the end of this document marked with a *).*

Do I have to take part?

No, you are not obliged to take part, participation is done on a purely voluntary basis and it is up to you to decide to join the study. If you agree to take part, we will then ask you to sign a consent form. **You are free to withdraw at any time, without giving a reason. This would not affect the standard of any NHS care you receive.**

What will happen to me if I take part?

We'll arrange a convenient date and time for an interview, which will take place in a public venue, such as a local community centre. A suitable venue will be discussed and selected depending upon where you live and when you are available. The interview will be audio-recorded (sound only, no pictures) so that we can transcribe (type up) what was said in the interview. The interview will explore your views and thoughts on the following: how you view mental health and mental illness; what you perceive to be the causes of emotional / psychological distress; what knowledge you have of mental health policy and services; what sources of help might exist. The interview is likely to last between 30 and 90 minutes.

Are there any payments or payment of expenses?

Yes. You will receive an 'inconvenience allowance' of £15 for taking part in the research. This will be given to you at the interview. There will be no

payment of expenses on top of this and we will attempt to interview you at a local venue in order to minimise any cost to you of getting there.

If you are interested in taking part then please either post back the ‘expression of interest form’ in the freepost envelope provided, call Sue Brown on [mobile telephone number removed for appendix] or e-mail the research team at lqxsb5@nottingham.ac.uk. We will send you further information and arrange to have a chat about the project, to answer any questions you may have. By expressing interest, you are not obliged to take part, this will simply let us know that you are interested and that you would like more information.

Thank you for your time.

**If you do not meet the above criteria but are interested in taking part then you may still be eligible to be part of the study. If you have recently been to see your GP in relation to psychological or emotional distress for the first time, or indeed if you are a GP or other health care professional, then you may be able to take part in the study but in a different group. Please call Sue Brown on 0115 9515227 to discuss this and receive additional information.*

Unfortunately we are unable to interview people who are under 18 or who do not live within the boundaries of NHS Nottingham City.

Appendix 2



Expression of interest form

Study title: Help-seeking behaviour of people experiencing psychological distress

If you have read the leaflet about our study, and would like to receive more information (so that you can decide about taking part) then please complete and return this form, in the freepost envelope provided.

Name:.....

Address:

.....

.....

Postcode:.....

*Land line telephone number.....

and/or

*Mobile telephone number

Please indicate which number you would prefer to be called on, by placing a star () after it.

If there is a best time of day to call you, please indicate when:

.....

If there is a best day of the week to call you, please indicate when:

.....

I would like to receive more information about the study, along with a follow-up call that gives me a chance to ask questions about it. I confirm I meet the following study criteria:

- I am over 18 (or 18 years old exactly)
- I am not a mental health professional, or a health care professional
- I live within the boundaries of NHS Nottingham City (at the above address)
- I have never been to my GP in relation to psychological or emotional distress

Signed:.....

Date: (optional)

Appendix 3



Participant Information Sheet

Study title: Help-seeking behaviour of people experiencing psychological distress

Researchers: Ian Shaw & Susan Brown

We would like to invite you to take part in a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. **One of our research team will be happy to go through this information sheet with you and answer any questions you have.** This would take about 10 minutes. We are happy to do this over the phone or face to face, and will call you in a few days to discuss your preference. Feel free to talk to others about the study if you wish. You will find our contact details at the end of this sheet, should you wish to contact us. This sheet tells you the purpose of this study and what will happen to you if you take part, and gives you more detailed information about the conduct of the study. If there is anything that is not clear then please do mention it, and we will discuss it with you further.

What is the purpose of this study?

This project will examine beliefs about mental health and mental illness, and whether these beliefs affect how people who are experiencing psychological distress seek help. The aim is to discover more about why certain paths are chosen (such as visiting a General Practitioner or 'GP') by some and not others. A lot is known about different patterns of help-seeking, such as differences between men and women, but not much is known about why these differences exist, and that is what this project will begin to examine.

This project is being done as the basis of an educational degree that is at Doctoral level (that is, it is part of a Philosophy Doctorate or 'Ph.D.').

Why me?

The starting point of this project is to examine what the general public thinks about mental health and mental illness, and this is where you come in. You have been invited to take part because you meet the following criteria:

- you live within the boundaries of NHS Nottingham City (your household was chosen at random)
- you have confirmed that you have not been to your GP in relation to psychological or emotional distress
- you have confirmed that you are not a mental health or health care professional.

We are talking to various people who meet the above criteria, and who are selected at random.

Do I have to take part?

No, you are not obliged to take part, participation is done on a purely voluntary basis and it is up to you to decide to join the study. If you agree to take part, we will then ask you to sign a consent form. **You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive from the NHS.**

What will happen to me if I take part?

Interview

We'll arrange a convenient date and time for interview, which will take place in your home unless you would prefer to be interviewed elsewhere (if this is the case we will select a public place, such as a local community centre). The interview will be audio-recorded (sound only, no pictures) so that we can transcribe (type up) what was said in the interview. The interview will explore: what knowledge you have of mental health policy and services; how you view mental health and mental illness; what you perceive to be the causes of emotional / psychological distress, and what treatments are available; what

non-medical resources exist. The interview is likely to last between 30 and 90 minutes. This is the main part of the research, and if you wish, this can be the end point of your involvement in the research.

The 'data' (that is, what was said in the interview) will then be anonymised, and will be added to other interview data, to be analysed by a member of the research team. Data collected may be used for future research in the same area, though this will not require any additional involvement on your part.

Summary of the findings

If you wish, you can receive a short written summary of the overall research findings at the end of the study. If you would like to receive this, please indicate so on the consent form. This is likely to be sent to you around September 2011.

Some participants may wish to provide take part in an extra stage in the study. This will now be discussed. This extra stage is voluntary and you do not need to take part, even if you have been interviewed.

'Participant validation' (extra stage)

Once the interviews have all been analysed, we will contact some participants to discuss the analysis based upon their interview (and how it fits in with the overall project). This is called 'participant validation' and it gives you a chance to say whether or not you think we have understood and interpreted what you said, correctly. It also gives you a chance to comment on what you think of the findings. By including this stage we are able to build in useful feedback into the write-up. This is likely to happen up to 6 months after the interview.

Are there any payments or payment of expenses?

Yes. You will receive an 'inconvenience allowance' of £15 for taking part in the research. This will be given to you at the beginning of the interview. There will be no payment of expenses as the interview is likely to take place in your home. If it takes place outside of your home then expenses will be discussed whilst making interview arrangements.

What are possible risks and disadvantages of taking part?

There are no likely disadvantages of taking part. Talking about mental health and illness involves conveying your thoughts and opinions openly and may, in some cases, be uncomfortable for some people and so you should think about this as one possible risk. You are not expected to talk about anything that you are not comfortable talking about, and if you feel that you don't want to carry on with the interview at any point, then we can stop it immediately (with no negative consequences). This is discussed in more depth in the section entitled 'harm'.

What are the possible benefits of taking part?

There are no therapeutic benefits to taking part, although some people enjoy the experience of being interviewed and having someone listen to them. The research may be used to make recommendations for service provision, although it is likely that any changes are experienced in the short term and any changes that do occur might not affect you personally.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

Anything you say during the interview will be confidential and your personal details will not be stored alongside what you say in the interview. As soon as the interview has taken place, the transcript of your interview will be given a pseudonym, and from then on, analysis will take place anonymously. Some quotes may be used in the write-up and in future publishing, however any identifying details (such as names, places and other identifiable data) will be anonymised so that it's not possible to identify you based on what is quoted.

The only occasion on which anonymity is not assured, is if you reveal something during the interview that indicates someone (you, or someone else including any child) is in significant danger of harm, or in the event of disclosure of a 'serious' crime. In this instance, the research team will consider whether disclosure of this information is necessary in order to prevent such

harm from taking place, or whether such information is in the public interest. Any disclosure would take place after careful consideration by the research team, on a case-by-case basis, taking into account the degree of severity of threat to safety and/or the ‘seriousness’ of the crime. This could mean passing on your disclosure to the relevant authorities. Any decision to disclose such information will be communicated to you.

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

If you wish to withdraw from the study, then you can do so immediately and no new data will be collected. Data collected up to that point will be retained in the study and anonymised (so that no one will be able to identify you from it).

What if there is a problem or I want to make a complaint?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions on 0115 9515227. If you wish to make a complaint then you should contact the Chief Investigator, Professor Ian Shaw on 0115 9515409 or via e-mail at ian.shaw@nottingham.ac.uk. Alternatively, you may contact Dr Anthony Fitzpatrick, Research Ethics Officer, on 0115 951 5230 or via e-mail at tony.fitzpatrick@nottingham.ac.uk.

Harm

It is extremely unlikely that any harm will come to you just as a result of taking part in this interview. You will not be expected to disclose information you are unwilling to disclose. In the unlikely event that the interview does cause you distress, you are welcome to end the interview at any time, at which point you will be given the opportunity to discuss your distress and whether you wish someone to be contacted on your behalf (such as your GP or a close friend or family member).

What will happen to the results of the research study?

The results will be fed back to NHS Nottingham City in written format and also to healthcare professionals within NHS Nottingham City, at a workshop. The results will also be written up in the PhD thesis, compiled into articles for

journals and other publications, and also presented at conferences. Anonymity will be ensured at all times.

Who is organising and funding the research?

The research is being organised and based at the University of Nottingham. It is jointly funded by the Economic and Social Research Council (ESRC) and the National Health Service (NHS).

Who has reviewed the study?

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

Thank you for taking the trouble to read through this information sheet. If you now agree to take part in the research and sign the consent form you will be given a copy of the consent form and this information sheet to keep for reference. If you would like to contact a member of the research team, then please feel free to call Sue Brown on 0115 9515227 or via e-mail at lqxsb5@nottingham.ac.uk.

Appendix 4



Study leaflet

Study title: Help-seeking behaviour of people experiencing psychological distress

We would like to invite you to take part in a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Here are some details about the study. **If you are interested then please read the enclosed Participant Information Sheet and complete the Expression of Interest form in the prepaid envelope provided. A member of the research team will then contact you to discuss the project and answer any questions you may have so far.** Asking for extra information does not constitute an agreement to take part in the study, it just means you are interested in finding out more, and this is why we'll contact you.

Here are some things you should know about the study:

What is the purpose of this study?

This project will examine how people who are experiencing psychological distress seek help, to discover more about why certain paths are chosen (such as visiting a General Practitioner or 'GP') by some and not others. A lot is known about different patterns of help-seeking, such as differences between men and women, but not much is known about why these differences exist, and that is what this project will begin to examine.

Why me?

You have been invited to take part because you meet the main inclusion criterion for the project; that is, you are currently seeking (or have recently sought) help for psychological or emotional distress, from your GP. Your GP

(along with other GPs within NHS Nottingham City) has been asked to pass leaflets to patients who meet this criterion, and so this is being done in various GP surgeries within Nottingham City.

Do I have to take part?

No, you are not obliged to take part, participation is done on a purely voluntary basis and it is up to you to decide to join the study. If you agree to take part, we will then ask you to sign a consent form. **You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.**

What will happen to me if I take part?

We'll arrange a convenient date and time for an interview. The interview will be audio-recorded (sound only, no pictures) so that we can transcribe (type up) what was said in the interview. The interview will explore: how you came to your decision to go to your GP (the story that led up to your decision); what expectations you had; whether any other sources of help had already been tried; and what you think about the topic of mental health more generally. The interview is likely to last between 30 and 90 minutes.

If you are interested in taking part then please complete an expression of interest form and send it back to the research team, and read the Participant Information Sheet that was included in this pack. One of our members will contact you to answer any questions you might have about the study, about the information you have received so far, and any other questions you may have. In the meantime, if you would like to contact the research team directly, then please call Sue Brown on 0115 9515227 or e-mail lqxsb5@nottingham.ac.uk.

Thank you for your time.

Appendix 5



Expression of interest form

Study title: Help-seeking behaviour of people experiencing psychological distress

If you have read the leaflet about our study, and are thinking about taking part (or would simply like to know more) then please complete and return this form, in the prepaid envelope provided.

Name:.....

Address:

.....

.....

Postcode:.....

*Land line telephone number.....

*Mobile telephone number

Please indicate which number you would prefer to be called on, by placing a star () after it.

If there is a best time of day to call you, please indicate when:

.....

If there is a best day of the week to call you, please indicate when:

.....

I am interested in the study and would like to express my interest so that I can receive a follow-up call that gives me a chance to ask questions about it. I confirm that I meet the following study criteria:

- I am over 18 (or 18 years old exactly)
- I am not a mental health professional, or a health care professional
- I live within the boundaries of NHS Nottingham City (at the above address)
- I have recently been to my GP in relation to psychological or emotional distress, for the first time

Signed: (name)

Date: (optional)

Appendix 6



Participant Information Sheet

Study title: Help-seeking behaviour of people experiencing psychological distress

Researchers: Ian Shaw & Susan Brown

We would like to invite you to take part in a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. **One of our research team will be happy to go through this information sheet with you and answer any questions you have.** This would take about 10 minutes. We are happy to do this over the phone or face to face, and will call you in a few days to discuss your preference. Feel free to talk to others about the study if you wish. You will find our contact details at the end of this sheet, should you wish to contact us.

This sheet tells you the purpose of this study and what will happen to you if you take part, and gives you more detailed information about the conduct of the study. If there is anything that is not clear then please do mention it, and we will discuss it with you further.

What is the purpose of this study?

This project will examine how people who are experiencing psychological distress seek help, to discover more about why certain paths are chosen (such as visiting a General Practitioner or 'GP') by some and not others. A lot is known about different patterns of help-seeking, such as differences between men and women, but not much is known about why these differences exist, and that is what this project will begin to examine.

This project is being done as the basis of an educational degree that is at Doctoral level (that is, it is part of a Philosophy Doctorate or ‘Ph.D.’).

Why me?

You have been invited to take part because you meet the main inclusion criterion for the project; that is, you are currently seeking (or have recently sought) help for psychological or emotional distress, from your GP. Your GP (along with other GPs within NHS Nottingham City) has been asked to pass leaflets to patients who meet this criterion, and so this is being done in various GP surgeries within Nottingham City.

Do I have to take part?

No, you are not obliged to take part, participation is done on a purely voluntary basis and it is up to you to decide to join the study. If you agree to take part, we will then ask you to sign a consent form. **You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.**

What will happen to me if I take part?

Interview

We’ll arrange a convenient date and time for interview, which will take place in your home unless you would prefer to be interviewed elsewhere (if this is the case we will select a public place, such as a local community centre). The interview will be audio-recorded (sound only, no pictures) so that we can transcribe (type up) what was said in the interview. The interview will explore: how you came to your decision to go to your GP (the story that led up to your decision); what expectations you had; whether any other sources of help had already been tried; and what you think about the topic of mental health more generally. The interview is likely to last between 30 and 90 minutes. This is the main part of the research, and if you wish, this can be the end point of your involvement in the research.

The ‘data’ (that is, what was said in the interview) will then be anonymised, and will be added to other interview data, to be analysed by a member of the

research team. Data collected may be used for future research on related topics, though this will not require any additional involvement on your part.

Summary of the findings

If you wish, you can receive a short written summary of the overall research findings at the end of the study. If you would like to receive this, please indicate so on the consent form. This is likely to be sent to you around September 2011 (due to the size of the project).

Some participants may wish to provide take part in an extra stage in the study. This will now be discussed. This extra stage is voluntary and you do not need to take part, even if you have been interviewed.

'Participant validation' (extra stage)

Once the interviews have all been analysed, we will contact some participants to discuss the analysis based upon their interview (and how it fits in with the overall project). This is called 'participant validation' and it gives you a chance to say whether or not you think we have understood and interpreted what you said, correctly. It also gives you a chance to comment on what you think of the findings. By including this stage we are able to build in useful feedback into the write-up. This is likely to happen up to 6 months after the interview.

Are there any payments or payment of expenses?

Yes. You will receive an 'inconvenience allowance' of £15 for taking part in the research. This will be given to you at the beginning of the interview. There will be no payment of expenses as the interview is likely to take place in your home. If it takes place outside of your home then expenses will be discussed whilst making interview arrangements.

What are possible risks and disadvantages of taking part?

There are no likely disadvantages of taking part. It is possible, however, that you might experience distress whilst recalling painful or difficult experiences, and so you should think about this as one possible risk. You are not expected to talk about anything that you are not comfortable talking about, and if you feel

that you don't want to carry on with the interview at any point, then we can stop it immediately (with no negative consequences). This is discussed in more depth in the section entitled 'harm'.

What are the possible benefits of taking part?

There are no therapeutic benefits to taking part, although some people enjoy the experience of being interviewed and having someone listen to them. The research may be used to make recommendations for service provision, although it is likely that any changes are experienced in the short term and any changes that do occur might not affect you personally.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. **We will tell your GP that you are taking part unless you specify that you don't want us to.** You will be invited to confirm this at the point of giving consent to take part in the study (there is a box on the consent form that allows you to choose whether or not they are told). Your GP will **not** be given any information about what you say in the interview, they will simply be told that you have taken part in the study.

Anything you say during the interview will be confidential and your personal details will not be stored alongside what you say in the interview. As soon as the interview has taken place, the transcript of your interview will be given a pseudonym, and from then on, analysis will take place anonymously.

Some quotes may be used in the write-up and in future publishing, however any identifying details (such as names, places and other identifiable data) will be anonymised so that it's not possible to identify you based on what is quoted.

The only occasion on which anonymity is not assured, is if you reveal something during the interview that indicates someone (you, or someone else including any child) is in significant danger of harm, or in the event of disclosure of a 'serious' crime. In this instance, the research team will consider whether disclosure of this information is necessary in order to prevent such harm from taking place, or whether such information is in the public interest. Any disclosure would take place after careful consideration by the research

team, on a case-by-case basis, taking into account the degree of severity of threat to safety and/or the ‘seriousness’ of the crime. This could mean passing on your disclosure to the relevant authorities. Any decision to disclose such information will be communicated to you.

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

If you wish to withdraw from the study, then you can do so immediately and no new data will be collected. Data collected up to that point will be retained in the study and anonymised (so that no one will be able to identify you from it).

What if there is a problem or I want to make a complaint?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions on 0115 9515227. If you wish to make a complaint then you should contact the Chief Investigator, Professor Ian Shaw on 0115 9515409 or via e-mail at ian.shaw@nottingham.ac.uk. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from 0115 9515227 or your GP surgery.

Harm

It is extremely unlikely that any harm will come to you just as a result of taking part in this interview. You will not be expected to disclose information you are unwilling to disclose. In the unlikely event that the interview does cause you distress, you are welcome to end the interview at any time, at which point you will be given the opportunity to discuss your distress and whether you wish someone to be contacted on your behalf (such as your GP or a close friend or family member).

What will happen to the results of the research study?

The results will be fed back to NHS Nottingham City in written format and also to healthcare professionals within NHS Nottingham City, at a workshop. The results will also be written up in the PhD thesis, compiled into articles for journals and other publications, and also presented at conferences. Anonymity will be ensured at all times.

Who is organising and funding the research?

The research is being organised and based at the University of Nottingham. It is jointly funded by the Economic and Social Research Council (ESRC) and the National Health Service (NHS).

Who has reviewed the study?

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

Thank you for taking the trouble to read through this information sheet. If you now agree to take part in the research and sign the consent form you will be given a copy of the consent form and this information sheet to keep for reference. If you would like to contact a member of the research team, then please feel free to call Sue Brown on 0115 9515227 or via e-mail at lqxsb5@nottingham.ac.uk.

Appendix 7

Participants' demographic information

Lay participants

Julia: female aged 50; self-employed; married with family; white British

Phil: male aged 56; self-employed; separated with family; white British

Sarah: female aged 41; employed full time; single; white British

Anthony: male aged 21; student; single; white British

Kate: female aged 21; student; single; white British

Dennis: male aged 63; semi-retired; married with family; white British

Michelle: female aged 22; student; single; white British

Nell: female aged 80; retired; cohabiting; white British

Diane: female aged 52; unemployed (high SES); married with family; white British

Lay participants who could be reclassified as help-seekers

Anita: female aged 41; employed full time; married with family; British Indian

Sadie: female aged 33; unemployed; single parent; white British

Help-seeker participants

Debbie: female aged 46; employed part-time; single parent; white British

Dylan: male aged 38; unemployed; single; white British (Irish descent)

Cath: female aged 58; employed full time; married with family; white British

Sally Anne: female aged 66; retired; widowed; white British

Patrick: male aged 71; retired; widowed; white British

Tanya: female aged 44; unemployed; single parent; white British

Anna: female aged 39; unemployed; cohabiting; white British

Antonio: male aged 37; employed part-time; married with family; Italian

Kara: female aged 22; employed full time; cohabiting with family; white British

All names given above are pseudonyms.

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