

Explaining non-help-seeking amongst young adults with mental distress: a dynamic interpretive model of illness behaviour

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Abstract Mental disorder is common amongst young adults and is associated with many adverse outcomes. Data, however, indicate that young adults are particularly unlikely to seek help for such distress. This paper describes a qualitative study of 23 young adults (aged 16 to 24 years) with mental distress. Interviewing was used to obtain detailed narratives of illness behaviour and to explore reasons for non-help-seeking. Help-seekers and non-help-seekers were interviewed. The findings allowed development of an explanatory model – the cycle of avoidance (COA) – which contributes towards attempts to provide a dynamic understanding of help-seeking behaviour. Dominant approaches tend to be deterministic and static and to account for non-help-seeking in terms of ‘barriers’ to care, which although easily translated into targets for policy intervention, are superficial representations of complex issues. The COA conceptualises help-seeking as a circular process and offers a model of ‘non-help-seeking’ in which lay conceptions of mental distress, the social meanings attached to ‘help-seeking’ and treatment, and the purposeful action of individuals, assume central importance. Although derived in the context of young adulthood and mental distress, this model may have wider applicability as a theoretical template for explaining non-help-seeking in other age groups and conditions, and other illness behaviours.

Keywords: illness behaviour, help-seeking, mental distress, young adults

Introduction

Mental disorder is common amongst young people and is associated with significant impairment and disability, particularly in relation to work, education and social interaction (Wittchen *et al.* 1998). At the same time, epidemiological data reveal low rates of help-seeking. As few as 17 per cent of young adults with mental distress (Rickwood and Braithwaite 1994) and fewer than a third of those with a clinically defined disorder may seek healthcare (Aalto-Setälä *et al.* 2002, Kessler and Walters 1998). These estimates for young adults are much lower than comparable figures for all adults. In fact, large-scale

surveys of all adults reveal an association between help-seeking and age whereby help-seeking is least likely to occur in those aged 16–24 years (Andrews *et al.* 2001, Olfson and Klerman 1992).

A recent review has shown that a large literature from a range of disciplines has sought to understand the factors influencing service utilisation (Young 2004). Within this, two differing sociological approaches can be identified, which offer a means of explaining the ‘iceberg’ of untreated psychiatric morbidity in young adults – the ‘dominant’ and ‘dynamic’ approaches (Pescosolido 1991, Pescosolido and Boyer 1999).

The ‘dominant’ positivistic approach explores differences in the characteristics of users and non-users of medical services. Deterministic models provide a ‘profile of service users’ (Pescosolido and Boyer 1999) and identify propensities to help-seeking to predict patterns of service usage (Andersen 1968, Rosenstock 1966). Service-use is thus accounted for by broad structural, psychological or demographic cues/barriers, sometimes in the form of a cost-benefit analysis (Pescosolido 1992). In the socio-behavioural model (Andersen 1968, Andersen 1995), for example, the societal system and individual factors underlie decisions about whether to seek help. Individual beliefs are measured using proxy variables that assume individuals share beliefs by virtue of broad socio-demographic variables. Help-seeking is determined by practical/structural issues such as access and cost – ‘barriers’ to care.

Critiques of dominant approaches (Dingwall 1976, Pescosolido 1992) have given rise to more dynamic conceptualisations. The sociological study of illness behaviour identifies help-seeking as part of a broader, socially embedded ‘illness career’. Help-seeking is then a social *process* and individuals’ pathways from the community to treatment are explored. The focus is on how symptoms are interpreted and managed by individuals and communities (Clausen and Yarrow 1955, Horwitz 1977). Lay diagnosis is the crucial first step of help-seeking and may be complicated by normalisation, denial and delay (Dingwall 1976, Freidson 1970, Mechanic 1968, Suchman 1965, Zola 1975). Illness behaviour is a process of ‘adaptation’ to symptoms (Alonzo 1984, Mechanic 1968) and help-seeking is one of various responses to illness alongside self-care, accommodation and ‘coping’ (Dingwall 1976, Mechanic 1968, Pescosolido 1991). Lay people assume an important role as carers and referral networks (Freidson 1970, Horwitz 1977, Pescosolido 1991, Zola 1978). A moral dimension is apparent, with actions being constrained by notions of normality and deviance, stigma etc. (Dingwall 1976, Freidson 1970). Help-seeking becomes a question of ‘when’/‘how’ rather than ‘if’ help is sought (Zola 1978).

Most attempts to develop ‘dynamic’ models specify a series of stages an individual must pass through as they cope with illness (McKinlay 1972, Suchman 1965). These models have been criticised for being rigid (Pescosolido and Boyer 1999), linear, behaviourist and giving primacy to medical definitions and perspectives (Dingwall 1976). Non-help-seeking remains couched in terms of ‘barriers’ to care, but broadened to include cultural knowledge and values. More recent developments, including Dingwall’s interpretivist model of illness action (Dingwall 1976) and Pescosolido’s network-episode (NEM) model (Pescosolido 1991, 1992) assert that illness is understood and managed through social interaction and cultural routines. They conceptualise illness behaviour as a context-bound, interactive social process that is shaped by agency and social networks rather than a deterministic response. Illness behaviour is not a simple decision about professional help-seeking but a multi-faceted, protracted career composed of a plurality of strategies and people consulted during the process of coping with symptoms.

Dingwall (1976) describes illness behaviour as purposeful social action contingent upon the meanings attributed to categories of symptoms in a three-stage process of evaluating

symptoms, deciding to act, and monitoring the effects of action. His model allows repeated and circular movement through these stages as new symptoms or unsuccessful actions require new approaches. Pescosolido's (1991, 1992) work focuses on social networks, emphasising the dynamic nature of lay referral as a *mechanism* rather than an *influence* on an individual's decision-making. The NEM has mostly mapped patterns of network contacts and quantified the amount of variance explained (Pescosolido 1992, Pescosolido *et al.* 1998), though Pescosolido (1991) advocates a mixed-methods approach incorporating qualitative research.

Empirical application in mental health research

Help-seeking in response to mental disorder has served as a case study for theoretical sociology (Freidson 1970, Mechanic 1968) but most recent empirical research follows the dominant approach and measures help-seeking as a single outcome using static cross-sectional surveys (Horwitz 1996). Perceived need and cultural and demographic factors are associated with use of health services by those with mental disorder (Bebbington *et al.* 2000, Horwitz 1996) and help-seeking 'barriers' are identified (Meltzer *et al.* 2000, Wells *et al.* 1994).

Empirical development of the dynamic approach has been limited (Pescosolido and Boyer 1999). Clausen and Yarrow (1955) revealed that the pathways to hospital of men with schizophrenia were delayed because couples struggled to interpret the meaning of even severe symptoms and normalise them. Horwitz (1977) demonstrated a similar delay and how problem recognition and thresholds for help-seeking are shaped by the structure and nature of social networks. Others have also concluded that the *process* of help-seeking is protracted, haphazard and influenced by friends and family (Pescosolido *et al.* 1998), and that deciding what constitutes 'illness' may be the central challenge for people with mental distress (Prior *et al.* 2003, Rogers *et al.* 2001). However, these studies rarely include distressed non-help-seekers, despite this being a key limitation of earlier studies (Horwitz 1977). Most report hypothetical attitudes of community samples or patients who have sought medical help (Pescosolido *et al.* 1998, Pill *et al.* 2001, Prior *et al.* 2003, Rogers *et al.* 2001). Pescosolido and Boyer conclude: 'a great deal is known about the use of mental health services by different social groups, but we are far from understanding the nature of the process and timing by which people reach treatment in the mental health system' (1999: 410).

Developing an alternative perspective

While the ground has been laid for a dynamic understanding of help-seeking, empirical development of this has been inadequate (Pescosolido and Boyer 1999). Dominant models retain prominence despite their determinism and more limited explanatory potential as complex beliefs and actions become reduced to descriptive categories, and the concept of 'barriers' as the main explanation for non-help-seeking has scarcely been challenged. Although qualitative medical sociologists originally instigated the dynamic approach, the most recent significant attempt at devising a dynamic model of illness behaviour (the NEM) has been developed mostly within the quantitative tradition.

This paper attempts to respond to these issues by presenting a dynamic interpretive account of illness behaviour in response to mental disorder. This was developed inductively through in-depth qualitative research with distressed young adults, aged 16–24 years. The research aimed to understand help-seeking choices, including reasons for *not* seeking help, and included those who had and had not sought help. It therefore differs from existing approaches (dominant and dynamic), which tend to track pathways to care, by offering explanation of non-help-seeking.

Methods

This paper is based on in-depth interviews that were conducted with mentally distressed 16–24 year olds, as part of a study that also involved a population survey to assess the prevalence of distress and help-seeking (Biddle *et al.* 2004). Qualitative methods were selected to examine illness behaviour as a process set within the social context of young adulthood. The research was conducted within the interpretive tradition, focusing on young adults' beliefs and theories about mental distress and help-seeking, and their attempts to interpret and attach meanings to symptoms. A central goal was theory building, and principles of grounded theory (Glaser and Strauss 1967, Strauss and Corbin 1990) were used to achieve this.

Sampling

The population survey (n=3,004) provided a sampling frame for the qualitative research. The survey contained the General Health Questionnaire (GHQ-12), a well-validated tool that enquires about neurotic symptoms in order to identify 'cases' with probable mental disorder who would benefit from discussing these with a doctor (Goldberg and Williams 1988). Respondents were sampled from those identified as GHQ 'cases' or who reported having been diagnosed and treated for mental disorder in the past. Mental distress and interviewees' likely 'need' for help were thus defined according to clinical criteria. 'Caseness' was further verified at the interview using the Clinical Interview Schedule revised (CIS-R) (Lewis *et al.* 1992).

Maximum variation and purposive sampling were employed to expand the generality of the findings and to be responsive to emerging themes, hypotheses and gaps in understanding, drawing on information provided by the survey. Data available for each individual included: socio-demographic characteristics; past and current distress; whether, and from whom, help had been sought; reasons for non-help-seeking, and accounts of self-medication and coping.

Help-seeking and non-help-seeking cases from both genders, across the study age range, and with varying severities of distress were sampled (Table 1). Help-seekers were defined as those who had sought 'help or advice' for their distress from a range of sources – from friends, through teachers and the voluntary sector to healthcare professionals. Individuals seeking informal help were recruited as well as those attending formal services. Groups who were difficult to recruit were sampled disproportionately until all the main categories of respondents were represented. Sampling continued until similar themes were re-emerging with each interview, and negative cases (*e.g.* males with apparently direct pathways to help) had been explored.

Data collection

In-depth semi-structured interviews were used to obtain detailed narratives of the illness behaviour that accompanied informants' episodes of mental distress. Interviews were conducted by LB in small sets, each interspersed by data analysis. They were audio-taped and lasted between one and two hours. A topic guide was used but issues were allowed to emerge naturally. This evolved to incorporate emerging themes and questions. The main topics explored were: young adults' concepts of mental distress and theories about cause, prognosis, and curability; interpretation of and responses to symptoms; perceptions of need for help; perceived outcomes of help-seeking; reasons for help-seeking or other actions, including possible 'barriers' and 'triggers'; perceptions of help sources (formal and informal); involvement and responses of family, friends and peers; and experiences of help-seeking. Prompting ensured all areas were explored in sufficient depth.

Table 1 *Characteristics of interviewees*

<i>Characteristic</i>	<i>N=23</i>
<i>Gender</i>	
Male	10
Female	13
<i>Age</i>	
16–19 yrs	12
20–24 yrs	11
<i>Parental social class</i>	
Non manual	16
Manual	6
Not reported	1
<i>Residencyⁱ</i>	
Parents	17
Friends/partner	6
Alone	2
<i>Occupationⁱ</i>	
Work full/part-time	10
Study full/part-time	12
Unemployed	3
House and family	1
<i>Mental distressⁱⁱ</i>	
Current cases	14
Past cases	8
Non-cases	2
<i>Indicators of severe distress</i>	
Suicidal thoughts ⁱⁱⁱ	14
Self-cutting	5
Overdosing	4
CIS-R score >20	5
<i>Help-seeking^{iv}</i>	
GP	12
Counselling	7
Samaritans	2
Lay group	15
None	3

ⁱCategories not mutually exclusive.

ⁱⁱA 'current case' is defined as someone scoring 12 or more on the Clinical Interview Schedule Revised (CIS-R) and/or currently receiving medical treatment for mental disorder and includes chronic cases. A score of 12 or more provides clinical evidence for neurotic mental disorder. Past cases were identified by evidence of past diagnosis and treatment. Two interviewees described transient 'stress' but did not screen as cases. General beliefs about mental distress and help-seeking were sought here.

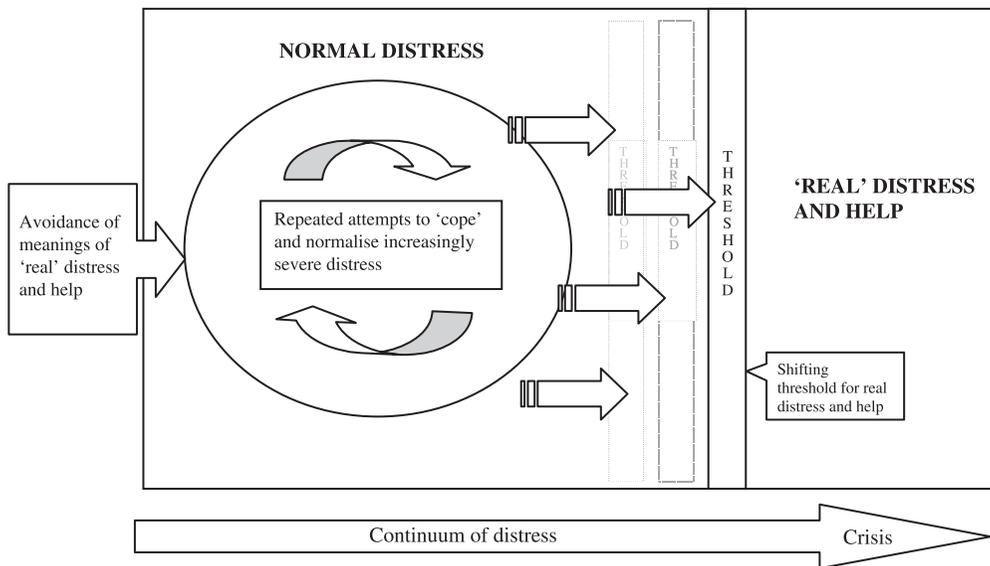
ⁱⁱⁱReported in questionnaire or at interview.

^{iv}Records number *ever* having used the help source. This includes isolated episodes after which the individual did not attend.

Analysis strategy

Interview transcripts were coded, at first using open and descriptive codes but increasingly identifying higher-level conceptual categories that encompassed the descriptive codes and the relationships between them. Descriptive accounts were produced for the main codes to examine their content, properties and dimensions. Conceptual codes were also considered according to type, noting whether they represented, for instance, a process, outcome, meaning or behaviour. In accordance with the method of constant comparison, codings within and across sets of transcripts were constantly compared for content. Analytical grids were used to identify key dimensions and explore patterns in the occurrence and co-occurrence of themes. The coding frame and links made between codes were repeatedly revised and codings adjusted until these were applied systematically to all transcripts. Other members of the research team independently coded data to check for consistency. Formal analysis was conducted between each set of interviews, resulting in five main sets of analyses. Sets were iterative and incremental with early analyses being mainly descriptive while later analyses achieved a more generalised and conceptual level of understanding. Particular attention was given to negative cases and the context surrounding them. The Atlas-ti programme was used to assist with data management.

It became apparent that thematic coding resulted in too much deconstruction of the data, distorting the process of help-seeking. Analysis therefore shifted to composing a longitudinal summary of the illness narrative of each interviewee, which tracked sequences of events alongside a description of the individual's beliefs, perspectives and behaviour over time. As case studies were produced and conceptual codes identified, a generalised conceptual model that could track the *process* of illness behaviour began to emerge – the Cycle of Avoidance (COA) (Figure 1). As this model developed, themes began to coalesce and the



The threshold shifts to include extreme notions of 'normality' as an individual seeks to avoid acknowledgement of 'real' distress. The threshold is crossed eventually through either the occurrence of crisis, the action of an external agency (e.g. lay group), or self-realisation often also precipitated by a crisis or similar event.

Figure 1 *The cycle of avoidance*

centrality of certain factors in driving behaviour became apparent. The COA was refined through further data collection and by returning frequently to existing cases to check for 'fit'.

Results

Thirteen pilot and 23 main study interviews were conducted. This paper draws on the latter, though pilot interviews were important in developing the topic guide. Interviews provided a diversity of narratives of illness behaviour ranging from complete, retrospective accounts of past cases, through longitudinal and on-going accounts of chronic cases containing shifts in perceptions, experience and behaviour, to embryonic and cross-sectional accounts of current cases at differing points within the illness trajectory. The dataset therefore allowed a view of both the help-seeking process and also detailed and naturalistic insights into its varying phases.

Interviewees' characteristics are summarised in Table 1. The sample had experienced considerable morbidity but a range of severity was included. Help-seeking status was not easily classified since illness behaviour displayed considerable fluidity and those who had received help had done so through varied pathways that could involve chance, choice and/or coercion. For example: some did not *seek* but became recipients of help; others withdrew from treatment despite continuing distress or did not seek help for subsequent episodes; and some were engaged in help-seeking decision-making at the time of interview.

Young adults' illness behaviour took the form of a cycle of avoidance – most narratives were characterised by long periods of non-help-seeking, even where help was eventually sought. This is shown as a theoretical model in Figure 1. The main components of the model are:

- a lay framework which operated as an interpretive schema for evaluating distress;
- an on-going, cyclical process of lay diagnosis involving repeated negotiation of the meanings of symptoms in order to avoid a diagnosis of 'real' distress;
- use of a range of strategies of normalisation and 'coping' to facilitate avoidance;
- a moveable threshold defining 'need' for help;
- the social meanings attached to 'help' and 'real' distress as factors driving the cycle (*i.e.* non-help-seeking) due to anticipated negative consequences of each, including identity shift, biographical disruption, and stigma.

These components are described below.

Lay framework: young adults' theories and beliefs about mental distress

Respondents described what they considered distress and depression to be. Their conceptualisations and theories provided the foundations for their illness behaviour as they established a framework for categorising distress and identifying the 'type' of distress that requires help (see Figure 2).

The polarised continuum

While mental distress can be viewed as a continuum of experience, respondents polarised this into two distinct categories with opposing characteristics. The largest was 'normal' distress – seen as universally and inevitably experienced throughout life in response to common life events and stresses. It was not regarded as serious or as illness, but as a 'phase'

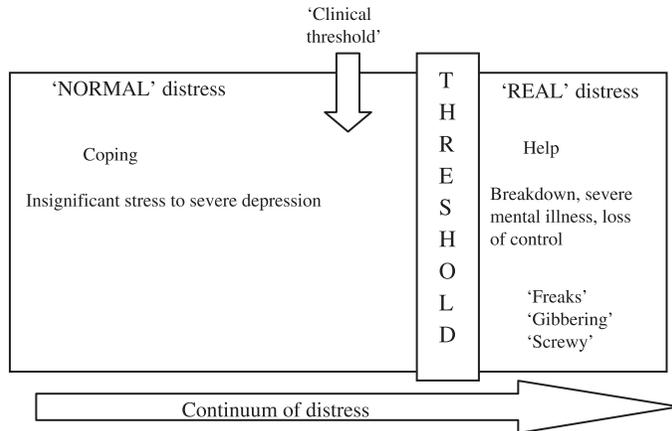


Figure 2 *Young adults' framework for understanding mental distress*

that would eventually 'pass'. The opposing category was described as 'real' or 'proper' distress. This was regarded as abnormal, rare, and often permanent and was the category respondents perceived to be mental illness.

'Real' distress was an extreme category, seen to include severe mental illnesses such as schizophrenia, psychosis and exceptional forms of depression such as 'manic' depression – 'manic' being used to denote an extreme form of symptoms rather than the clinical diagnoses.

LB: What does [real distress] make you think of?

Maybe people who's got voices in their heads.

LB: So quite extreme?

Yeah, yeah. Yeah, definitely. People that are paranoid I reckon, that's mental health (ID 22: female, 23yrs).

Respondents described various criteria for distinguishing 'real' from 'normal' distress and depression. To qualify as 'real', episodes had to be sufficiently severe and long-lasting, and to be accompanied by outwardly visible, constant, disabling, and pervasive symptoms. Also, 'reasons' for 'real' distress had to be unusually traumatic:

Everyone can get depressed so I don't really consider it illness unless they've got chronic depression where they're depressed all the time . . . when people just can't cope with simple situations and they can't see themselves getting out of bed in the morning (ID 12: female, 18yrs).

'Real distress' therefore was a category of severe mental disturbance characterised by 'breakdown' and inability to cope.

People with psychiatric illness generally can't control themselves that well, either the way they act or the way they behave . . . (they) are people who generally can't hack it almost. Their minds generally kind of break down and go through certain problems that drugs can overcome sometimes or, I don't know what they do in those places, electric shocks (ID 10: male, 16yrs).

'Normal' distress encompassed all residual forms of distress and mental disturbance that did not meet these extreme criteria. Even severe episodes became included in the category 'normal' and considered unproblematic.

You've got stress and then you can kind of go over the edge of stress and it's like mental problems . . .

LB: So how do you know whether you're just stressed or whether you've got mental problems?

I would say stressed is when you literally can't cope with getting up in the morning . . . You've got to that point then when you can't do anything, you don't want to go anywhere.

LB: So that's stress?

Yeah, to me, in my eyes.

LB: And how about mental problems? What would they be?

Oh um getting close to the edge and feeling life isn't worth living and contemplating taking your own life (ID 17: female, 23yrs).

'Normal' distress thus encompassed minor transient stress to severe depression, but this did not overlap with 'real' (illness) distress. Respondents perceived the two (binary) categories as divided by a solid threshold.

There's normal feelings of stress or depression or whatever that people just have at various points in their life and some people have more or worse or longer than others but that's not the same as illness, mental illness I mean, that's another category.

LB: But aren't they just degrees of the same thing?

Um, I don't think they're the same at all. I mean like mental illness is like breakdown, something that takes control of the person's life and that's different to feeling bad as part of life (ID 23: female, 24yrs).

Need for help

Respondents located the need for help with 'real' (*i.e.* extreme) distress only. In fact, this was a circular definition, with distress being regarded as real only when it was treated, while 'normal' distress was identified by 'coping'.

LB: When do you think someone needs to get help for something like depression?

I suppose when you're in quite a bad state . . . in the stages of manic depression I'd say you should get help (ID 16: male, 19yrs).

There was therefore a considerable gap between lay and clinical understandings of where along the continuum of distress the threshold for illness and need for help might lie. Interviewees' category of 'normal' (non-illness) distress included distress that would be regarded as clinically significant and the threshold for help was formulated as the point at which people cannot 'help themselves' and are in crisis.

That is when I see the time to go and get help is, when you see it as being too late and you've tried absolutely everything, there's nothing else you can do and you get trying to sort of take your own life sort of thing.

LB: Right so you would go for help before you got to that stage?

I think I'd consider it around that point (ID 1: Male, 20yrs).

Stigma

Stigma was a key factor in the framework. Numerous stigmatising labels were used to characterise those with 'real' distress (mental illness), including: being 'sick', 'screwy', or 'ill in the head' (ID 7, 8, 9, 10, 12), 'totally mental' (ID 12), 'gone up there' (ID 14), a 'freak', 'weird', or 'nutty' (ID 2, 3, 5, 6, 8, 10, 14, 18), 'gibbering' (ID 19), or a 'nutcase in a padded cell' (ID 10, 17). Conversely, attitudes towards 'normal' distress were dismissive and those who complained about this could be stigmatised for being non-genuine or a hypochondriac.

It has been asserted that such lay concepts of illness are central to how people interpret and respond to symptoms. Dingwall (1976) in particular frames illness behaviour as a form of social action constructed by the social meanings assigned to symptoms, and suggests that a focus on lay health beliefs and theories should be a 'prime task' of the medical sociologist because these are the basis and justification for all illness behaviour, from dismissal of symptoms, through self-medication to formal help-seeking. The validity of this perspective was evidenced in this study, as the conceptualisations of distress as described here were essential to respondents' personal narratives of distress and illness behaviour. It was within the context of the polarised framework that respondents tried to interpret and negotiate their own mental symptoms and made help-seeking decisions. These narratives are now detailed below.

Lay diagnosis: the avoidance of 'real' distress

The central feature of respondents' narratives was a process of lay diagnosis. This involved a struggle to assess where their distress fitted within the framework of 'normal' and 'real' distress. Essentially, they questioned whether their distress was *just* 'normal' and therefore of minor significance, or *bad enough* to be 'real' and to require action. Resolution of this was problematic for all respondents and complicated by a number of factors, yet how it was resolved was central to help-seeking due to the inextricable link between definitions of distress and perceptions of the need for help. These issues emerged both in the reflective retrospective accounts of past cases and were evident as ongoing dilemmas in the narratives of current and chronic cases.

The particular nature of mental symptoms presented a challenge. Many respondents struggled to evaluate the significance of subjective, non-visible 'feelings' that had a gradual or non-specific onset. Some did not consider their mental *feelings* to be symptoms at all. Where distress was recognised, the limitations of their binary framework and lack of benchmark for rating the significance of distress were striking as they struggled to identify where 'real' distress began:

There's feeling unhappy and there's being ill.

LB: So how do you distinguish the two?

By how long it lasts, by how intense it is, what effects it has, whether it's temporary or not . . . proper depression is much more than just a feeling, it's a state, a really overwhelming and oppressive state.

LB: So the two types aren't hard to tell apart then?

Hhh um no they are or they can be. I'm not sure because there have been times when I was depressed and I wondered whether I was or not. I mean I knew I was but I didn't know whether it was anything out of the ordinary or not – like proper depression if you see what I mean.

LB: So when does normal depression become something out of the ordinary?

Well that's the problem 'cos you can't exactly measure it. It's not an either or type thing that you either see or you don't like spots. I still find it hard to grasp just 'cos there are no definite boundaries for it or ways of knowing when it's real (ID 23: female, 24yrs).

Perpetuating this uncertainty was reluctance to arrive at a lay diagnosis of 'real' distress. Primarily, respondents wished to dissociate themselves from 'real' distress due to the negative meanings and outcomes that they assigned to this extreme category – in particular, the stigma and permanence associated with 'real' mental illness:

I tried to deny it [depression] because I just wanted to be normal like everyone else.

LB: Oh right, so you thought if you admitted you had depression you wouldn't be?

Yeah I'd just be inadequate (ID 16: male, 19yrs).

I didn't think I was mentally ill as such I just thought (.) mentally ill for me is like, that gives me like a picture of someone who's really screwy in the head. Mentally ill, mentally ill, it depends how you define mental illness I suppose.

LB: Um-hum. So how do you think it would have been right to define what you were going through?

Just a normal cloud of something, I don't know, I wouldn't call it mental illness (ID 7: male, 17yrs).

You really do have to live with it because it's like you become that person and there is no means of escape and so until you are 100 per cent sure that you are like that [have 'real' distress] you just don't want to become it . . . I wouldn't want to make a big fuss or have other people make a fuss in case it was a false alarm (ID 23: female, 24yrs).

At the same time, some were also reluctant to define their distress as 'real' in case they were stigmatised for attention-seeking or being a hypochondriac:

I wouldn't say I'm depressed, I would just say that I am really overstressed. But I suppose you could call it depression because the thoughts [of suicide] I get sometimes with it . . . I don't know because it is quite hard to decipher each one. I mean when do you say that stress is depression or depression is manic depression . . . and how do you say when somebody's upset or somebody's seriously depressed?

LB: Does that make it harder to cope with?

Yeah because in a way everybody says they're stressed so you kind of feel like you're being a bit like a hypochondriac (ID 15: female, 18yrs).

These data reinforce early theoretical discussions of illness behaviour in which it is noted that the act of lay diagnosis has a moral dimension that may result in denial or delay to avoid social disapproval (Dingwall 1976, Freidson 1970). Mental illness is pinpointed as an example of this (Mechanic 1968).

Normalisation and coping

Typically, respondents negotiated the meaning of their symptoms by normalising them – that is, defining them as 'normal', everyday distress. This usually resulted in a decision that

help was not needed or justified and distress was perceived as a transient phase that 'time would heal' (ID 9), they would 'grow out of' (ID 17), or 'had to suffer' (ID 10) – though this could be a long time. As theorised by Mechanic (1968), mental distress was particularly amenable to normalisation because of its gradual onset, casual usage of terms such as 'stress' and 'depression' in everyday life, and because the criteria for recognising 'real' distress were moveable and subject to interpretation. The concept of normalisation has been applied to lay diagnosis and help-seeking (Clausen and Yarrow 1955, Mechanic 1968) and response to chronic illness (Gerhardt 1989). The findings therefore fit with and elaborate upon an established frame of sociological explanation, since among these respondents several strategies of normalisation were apparent.

Application of alternative non-illness explanations

Alternative explanations were derived to rationalise symptoms and hence dismiss them. Young adults' distress was particularly amenable to this:

I just thought oh well I don't like going out, I don't want to see anyone, I don't want to do anything, may be that's just teenage years . . .

LB: Did you talk to anyone about how you were feeling?

Um, my mum, but she was like 'oh well you can't be depressed you're too young' (.) she goes 'you've got no problems', she says 'you're not (.) you only get depressed when you get above 30' . . .

LB: How did you feel when she said that?

I thought oh my gosh, I thought I must be imagining the whole thing . . . and I thought try to ignore it but it got really bad, I just wouldn't go out of the house and I took days off school and it was quite bad.

LB: What did your mum do then while you were taking days off school?

She just thought that I'd get over it, it was just a phase (ID 3: female, 20yrs).

Accommodation and coping

Examples of managing to 'cope' normally despite distress were used as evidence that distress could not be 'real':

I still managed to pay my bills, keep my mortgage going, work you know, bring up a little girl and when you think of it, well you know, I couldn't have been that depressed if I could do all that . . . I look back and think well was I really? You know, do I really suffer from that? (ID 9: female, 23yrs).

Emphasising and increasing the extreme nature of 'real' distress

However distressed they became, respondents could usually conceive of a more distressed or needy state beyond their own experience. This became their benchmark for 'real' distress, and thus they could accommodate and normalise their own distress repeatedly to avoid the need to seek help:

If you actually think about what depression really is then you don't come close . . . there's the sort of depression where you literally can't get out of bed and you've just had enough generally and I don't think I've ever really had that, so I wouldn't say I'm depressed. I'd say I've had a bad time of things for say longer than a couple of weeks or months or it's been a bad couple of months but I wouldn't say I'm actually depressed . . . I think I hit the middle of the scale. I don't think I was anyway near proper depressed. I don't think

I ever had a day where I couldn't get out of bed. I had days where I didn't want to and it was most days I woke up and just didn't look forward to the day and I didn't want to get out of bed because I just thought it was a pointless exercise (ID 1: male, 20yrs).

I had lost basically two and a half stone in six weeks and I kind of realised 'what are you doing to yourself' . . . and I thought I've got to sort myself out.

LB: Didn't you think about getting any help?

I didn't think I was that bad. I didn't think that it warranted wasting their [doctor] time . . . you know, I'm not three and a half stone and my hair's falling out (ID 17: female, 23yrs).

Defining 'need'

Need for help was juxtaposed with extreme images such as hospitalisation, thus allowing re-definition of the distress as 'normal'.

I had read some stuff before when I was trying to work out if there was anything wrong with me. It was stuff about depression and nervous breakdowns and stuff and how you might have to go to hospital and I think that's what put me off going (to GP), not because I was afraid it would happen to me, but I just thought well that is proper mental illness and I'm not like that, that's when you need medical help, so I can't need it, I'm not that bad (ID 23: female, 24yrs).

Temporalising

A definition of distress as 'normal' was maintained until 'realness' was proven, but the moveable nature of the criteria for 'real' distress and the fact that criteria such as 'not-coping' could only be determined when these points had passed, allowed interviewees to delay defining their distress as 'real' for long periods, if not indefinitely. For instance, severity was determined by waiting to see if distress could 'get worse'; permanence by waiting to see if it 'got better'; and not coping by waiting for cues such as 'rocking in a chair' (ID 23).

I've been feeling down for quite a long time now but I think of depression as more of a long-term thing, I would say years – months to years – whereas I am hoping that this is just overstress and that I am going to be able to de-stress soon and that I'm not going to feel like this anymore . . . I think only time will tell at the moment. If I get lower and lower and lower then it's gonna get to a point where I'm going to have to go and get help from somewhere, don't know where, but I might wake up tomorrow and feel on top of the world (ID 15: female, 18yrs).

I didn't see it as that serious to be honest.

LB: what would make it more serious?

Um I don't know it'd just be it'd be more like being more depressed or something 'cos it isn't just like the length of how long you're depressed, it's like how depressed you get.

LB: is that why you were saying earlier it's hard to know if it's normal or not?

Yeah it's kind of like you don't know how far depressed you can get until you are that far in depressed (ID 7: male, 17yrs).

The shifting threshold for 'real' distress and help-seeking

Help-seeking could be postponed almost indefinitely by continuing to find new explanations for distress being 'normal', even as worsening symptoms contradicted earlier normalisations.

I looked at what was happening around me and I would try and attribute it to friends or something in the family or my job. I had to give it a name (.) I had to give it a reason (.) I could say 'well it's my course, I'm not doing great in the course' . . .

LB: Does it make you look at it differently then if you can attach a reason to it?

Yeah. I'd think I hate going into college and try to focus more on improving what the course was like and things like that and expect it to ease and if it didn't I'd root around and find something else to put it on (ID 1: male, 20yrs).

Illness behaviour was a circular, on-going and protracted process of repeatedly trying to negotiate and re-negotiate often increasingly severe symptoms. This entailed reconsidering the boundaries between 'normal' and 'real' distress and with each cycle the threshold for 'real' distress and help-seeking could be shifted just beyond current experience. Therefore, as respondents engaged in this cycle of avoidance and as symptoms worsened, iterations of the cycle pushed the threshold towards increasingly severe levels of morbidity such as 'suicidal behaviour', 'hearing voices', 'nervous breakdown' or other crisis events. Some respondents (past and chronic cases) were able to reflect upon this. The 'realness' of their distress only became apparent because of the occurrence of a crisis during which help was often enforced:

I was really badly like depressed and I didn't go to the doctor's because I didn't think that it was um (.) oh well I didn't think I was ill. I didn't think I was ill so it ended up that I ended up in hospital [overdose] . . . I really needed to see for myself there was a problem. I think that was the hardest thing ever to actually realise. I mean it took me to go into hospital to realise (ID 3: female, 20yrs).

Normalisation thus had two important outcomes for help-seeking: symptoms were responded to with avoidance, inactivity and delay; and the threshold for help-seeking was moved progressively to higher levels of severity and even towards or beyond the point of crisis. These findings resonate with Clausen *et al.*'s (1955) classic study of mental illness in the family, where wives with mentally disordered husbands used normalisation to deny their symptoms and 'stretched the range of normality' until this was no longer possible.

Meanings of 'help' as drivers of non-help-seeking

Rather than simply following on from lay diagnosis in sequential fashion, decisions about seeking help were also central to lay diagnosis. Help-seeking was regarded as the act that would transform distress by moving it across the threshold and hence 'make' it real. This was because seeking help turned private reality into something public and official:

It's [help-seeking] like going to authority and saying (.) that just didn't seem the natural thing . . . It would have been like it was more out in the open. It would be (.) real. It's mainly to do with that 'cos I was in denial. I didn't want it to be real (ID 2: female, 19yrs).

Interviewees perceived the transformation of their distress into 'real' distress as highly significant and negative. They believed this, and hence help-seeking, would initiate an irreversible status passage from which undesirable outcomes would follow: frightening or disruptive treatments; a public and personal change of identity and record of treatment that would alter their biography; and the stigma of mental illness:

It makes it feel really real if you're having to see a doctor and be prescribed drugs just because you're feeling emotionally ill. I don't know, that really would make it hit home. I didn't really want to get to that stage.

LB: So seeking help would be quite a turning point?

Yeah it's (.) I think it's yeah quite a pivotal thing . . . it's a path I didn't really want to go down (ID 4: male, 21yrs).

I just didn't think about speaking to the doctor because I didn't want to be sectioned or anything. You know there is a stigma about psychological health. There's like a black, black cloud and as soon as you sort of fall under it everyone else runs for cover . . . I thought if I said anything to anyone I thought I was going to end up at [local psychiatric hospital] having electric shock treatment (ID 19: male, 23yrs).

The underlying concern was that help-seeking would make the distress longterm and so *worse* rather than offering the prospect of recovery. Not seeking help was therefore the ultimate strategy of normalisation and respondents engaged in a range of coping strategies (some harmful) to maintain this and so avoid the status passage:

I didn't know what to do or where to go but then again at the time I thought I was doing the right thing. I thought harming myself was the right thing, it was my solution, my way of coping with things and keeping things going rather than going somewhere for help 'cos that's what I wanted. I wanted things back the way they were beforehand so I wanted to try to keep things normal and to keep sane.

LB: Keep sane?

Yeah, it's like another person might just have another drink – think oh that's alright I'll have a drink and everything will be alright. I wanted it to be alright. I didn't want to have to take a backwards step, to get help.

LB: To seek help makes things not normal and makes you insane?

Well it's a sign that it's got to this extreme and things aren't gonna be just normal anymore (ID 13: female, 20yrs).

[Respondent provides narrative of attempts to 'cope'].

LB: But can't you be helped with feelings like that?

I'm not really sure, I mean yeah, there's always anti-depressants or whatever.

LB: So what makes you try your approach rather than that?

Well with my approach I'm trying to avoid that, well not specifically antidepressants just like the whole thing of being treated for depression . . . because once you go outside and get some sort of help or treatment it changes the whole thing. The feelings might not change but suddenly it's like official you know and that just makes you view the whole thing so differently and it makes it seem more real and permanent . . . because now you're a patient or whatever, you're being treated . . . It's almost like before you could have escaped it but once it's official you can't and you have to be a depressed person

because you've said you are and the doctors said you are and you can't try to convince yourself otherwise or leave it behind (ID 23: female, 24yrs).

These data overlap with the sociological literature addressing experiences of chronic illness (Charmaz 2000) – in particular Bury's (1982) notion of biographical disruption. Respondents pre-empted such disruption and attempted to avoid this. They were anxious to resist medicalisation of their distress, being perceptive about the possible consequences of being 'treated'. The observation that stigma is related to help-seeking is not new – particularly in relation to mental health (Freidson 1970, Phillips 1963) – but its importance as an explanation for non-help-seeking has recently been contested (Prior *et al.* 2003). Concerns about stigma, however, permeated these young adults' accounts and were a prominent reason underlying normalisation, non-help-seeking and avoidance of real distress. These findings provide evidence of the continued relevance and pivotal importance of stigma.

Discussion

This paper has described a qualitative study of the illness behaviour of young adults with mental distress and presented an alternative explanatory model of non-help-seeking – the cycle of avoidance (COA). The COA was derived inductively from analysis of participants' narratives of interpreting and responding to mental distress. Unlike other studies, which are restricted to the accounts of diagnosed patients (Clausen and Yarrow 1955, Pescosolido *et al.* 1998, Rogers *et al.* 2001), this study included non-help-seekers. Help-seeking was examined as a process within the context of a broader illness trajectory. The study and model therefore contribute towards providing a dynamic sociological understanding of help-seeking. Central to the COA are the social meanings attributed to illness and 'being helped' and how attempts to negotiate these drive illness actions. It therefore forwards the interpretive perspective, which has received less development in recent years.

Sociologists have long postulated that lay diagnosis is central to illness behaviour (Mechanic 1968, Zola 1975) and in this study respondents' narratives revolved around multiple attempts to interpret and negotiate the place of distress within a framework of 'normal' and 'real' distress. In keeping with recent studies (Prior *et al.* 2003, Rogers *et al.* 2001) lay diagnosis was a problem of classification – not merely the *ability* to recognise symptoms. This paper has further contributed to understanding lay diagnosis as a *process* by delineating the framework used by young adults to interpret mental distress and describing the strategies they employed to negotiate the challenges this presented. Well-established sociological concepts (normalisation and stigma) were major explanations for non-help-seeking, providing a recent empirical example of their centrality to illness behaviour. Themes typically associated with the experience of chronic illness were also important, suggesting these have wider relevance as motivations for not seeking help and re-emphasising the need to place help-seeking within the context of the broader illness career.

Several strategies were employed as measures of quality control, including: full tape-recording and transcription of interviews; computer software to facilitate comprehensiveness; application of principles of grounded theory and the constant comparative technique; and investigator triangulation to check reliability of data interpretation. The data are enhanced by being embedded within a mixed-method study. The survey provided a large, detailed sampling frame, which increased the opportunity for maximum variation and purposive sampling and provided access to individuals with undisclosed mental distress. While the sample is not large, its diversity enhances the likely transferability of findings and several

respondents provided narratives containing more than one episode for analysis. Triangulation with survey findings was also possible thus giving some indication of the model's external validity and generalisability.

Clinical implications

Low rates of help-seeking for mental disorder are of concern since mental disorder is a disabling yet treatable form of ill-health but, to date, there has been an incomplete understanding of the illness behaviours of those who do not seek help. This study begins to bridge this gap. The COA shows that young adults' illness behaviour in response to mental distress usually involves accommodating or denying illness rather than resolving it, even when symptoms become severe. Non-help-seekers may then be at risk of further morbidity from 'unhealthy' coping strategies such as self-harm and substance misuse, and of crises that timely help-seeking may have circumvented. The threshold for help-seeking may be pushed to a point where individuals struggle to initiate help-seeking.

While the COA demonstrates that normalisation can be pushed to extreme, even dangerous, endpoints, it also makes sense of this from a lay perspective as an act of 'anti-medicalisation'. It is important to acknowledge that not all episodes of distress involve a trajectory towards crisis. Many symptoms are self-remitting and relatively unproblematic. In such cases the cycle may be appropriate and reasonable. The helpfulness of pathologising distress that patients are able to tackle within normalised frames of reference has been questioned from sociological (Phelan and Link 1999) and medical (Heath 1999) viewpoints. The COA reinforces the need to balance clinical and lay perspectives when attempting to determine an appropriate threshold. Further research will be needed to explore individuals' experiences of help-seeking and treatment to investigate whether the anticipated status passage occurs and how this is experienced, and to ascertain at what point non-help-seeking becomes problematic.

Theoretical implications

The COA provides further evidence of the need for a dynamic approach to help-seeking. It illuminates the limitations of measuring help-seeking as a static, single outcome by contextualising help-seeking as part of a broader, protracted and fluid process of interpretation and varied actions. Within the genre of dynamic approaches, the COA supersedes 'stage' models, which depict illness behaviour as a linear, sequential process. It expands upon the circularity implied by Dingwall and Pescosolido because the threshold for help-seeking was shown to be continually shifting and the interpretation of symptoms (lay diagnosis) and decisions about whether to seek help were mutually reinforcing. Not only did lay diagnosis suggest whether or not distress was 'real' and required help, but the act of help-seeking itself played a pivotal role in defining 'realness', so decisions about whether to seek help were central to negotiating the meaning of illness. The COA thus emphasises there is multi-directional interaction between 'stages' and the artificiality of treating lay diagnosis and help-seeking decision-making as sequential phases.

The COA was derived from the accounts of non-help-seekers as well as help-seekers and so deals more adequately with the phenomenon of non-help-seeking than other models, which focus on the pathway to care as though this were an inevitable endpoint. Attempts to replicate the pathway approach in this study proved fruitless because such a pathway was indistinct. In fact, narratives were typified by non-resolution and avoidance of the pathway as illness behaviour was characterised by attempts to avoid a label of 'real' distress. The COA shows that individuals were instead tangled in loops before embarking on the pathway, and thus suggests opportunity for intervention.

The concept of barriers remains common currency as an explanation for non-help-seeking (Kasper 2000). However, 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. This is illustrated by Prior *et al.*'s (2003) study of lay attitudes to help-seeking for mental disorder in which they argue that lay diagnosis and not stigma is the key issue. This conclusion is reached by conceptualising stigma as a 'barrier' to disclosure and counting such references to 'stigma' in focus group transcripts. However, by exploring stigma as a normative belief system that is 'felt' or anticipated by reflexive social actors and may give rise to various social actions (Goffman 1984), this paper has demonstrated how stigma permeated the complex interpretive process involved in attempting to classify distress and negotiate the need for help. 'Barriers' are thus superficial representations of much more dynamic issues. The concept provides a convenient means of approaching help-seeking by exchanging complexity for crude 'measurable' categories but is reductive and does not engage with individuals' experiences of negotiating illness behaviour.

The COA demonstrates the insights that can be provided by a qualitative approach to understanding the decisions and actions of individuals confronted by illness. Most research addressing help-seeking for mental disorder is cross-sectional. Although some retrospective and longitudinal accounts contributed to the COA, follow-up interviews are required to take the model further and understand its implications. Follow-up of non-help-seekers could reveal how and when the cycle is sustained, perpetuated or broken, and detailed comparison of the narratives of help-seekers and non-help-seekers might illuminate opportunities for intervention. Research could also investigate the potential of the COA as a theoretical template for explaining help-seeking amongst other age groups and related illness behaviours such as acceptance of diagnosis and treatment compliance. The applicability of the COA outside the field of mental health, particularly to other stigmatising conditions, should also be examined. While there are specific features of mental distress that may have exacerbated the cycle, (e.g. the plurality of non-illness definitions available for symptoms and its occurrence as a continuum), normalisation and stigma – key components of the model – are well-established sociological concepts of relevance to symptoms of physical as well as mental illness.

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