

DClinPsy Portfolio

Volume 1 of 2

A portfolio submitted in partial fulfilment of the requirements of the University of Hertfordshire for the degree of DClinPsy including a thesis entitled:

An Interpretative Phenomenological Analysis of Young People's Experiences of Living with a Parent with Mental Health Difficulties

Cassie Bromley

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WRITTEN EXERCISE 1

Compare and contrast the construction of 'psychopathology' in adult and older adult mental health

Cassie Bromley

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Introduction

The construction of psychopathology has a far reaching impact and has provoked an enormous critique of the dominant bio-medical model and view of mental distress as an illness with a biological basis. However, despite the abundant literature critiquing the consequences of psychopathology on race, gender and class, little has addressed the differences in constructions of psychopathology across ages. This essay will attempt to review some of the predominant differences in adult and older mental health and highlight some of the similarities, with the aim of initiating discussion in a much neglected subject. After comparing and contrasting adult and older adult mental health difficulties, the implications for practice will be considered, with reference to a case example.

Before exploring the differences and similarities in mental health across ages, it is important to clarify what definition of psychopathology will be used and examine its assumptions. For the purpose of this essay psychopathology will refer to the Diagnostic and Statistical Manual IV (APA, 1994) description, as it is the dominant view in UK mental health services.

It is equally important to explore the construction of adult and older adult as this categorisation is central to the discussion. The inherent assumptions in such a distinction are crucial to understanding how and why differences in mental health difficulties may occur and whether categorisation is useful.

The construction of ‘psychopathology’

DSM-IV is essentially a descriptive system in which mental disorders are defined by a collection of behaviours. It is described by the American Psychiatry Association (1980, 1987, 1994) as a theoretical model of abnormality viewing mental disorders as naturally occurring objective entities amenable to empirical investigation. It is based on the bio-medical and reductionist view that locates problems within individuals, proposing that major mental disorders have a ‘substantial genetic component’ and are caused by ‘abnormalities in brain pathways’, and ‘imbalances in brain chemistry’ (APA, 2005).

Social constructionists believe there is no objective truth or reality outside of history, culture and social processes. In accordance with this philosophy, constructions are ways of understanding the world, formed through social interaction that privilege some patterns of social action whilst excluding others (Gergen, 1985: cited in Burr, 2003). Hence, Gergen (2001) describes psychopathology as a 'realist fallacy', in that it assumes problems exist independent of interpretation. This viewpoint is central to the critique of psychopathology as defined by DSM-IV.

Many criticisms of this dominant discourse have been levied, including the lack of scientific data supporting the categories of mental illness it defines and the circularity of reasoning it relies on (Boyle, 1990; Johnstone, 2000, Rogers & Pilgrim, 2005). Successive editions incorporate new categories and reject older ones, leading to the questioning of its scientific objectivity as categories are negotiated. A much cited example is the numerous people who were 'cured' overnight when homosexuality was dropped from the DSM in 1973 (Burr, 2003; Johnstone, 2000) Indeed, what most critics of the DSM and biomedical model argue for is recognition of the political and interpersonal influences that are present in any construction and relinquishing of the notion that it is objectively scientific (Boyle, 1990; Johnstone, 2000).

Caplan (1995: cited in Raskin & Lewandowski, 2000) describes her battle to keep categories which essentially pathologise women's experience out of DSM-IV, such as 'pre-menstrual syndrome' and 'self-defeating personality disorder'. This highlights the vulnerability of marginalised groups in mental health and the power of dominant social groups in construing difference as abnormal. It therefore becomes evident that illness is a social judgement (Burr, 2003), and varies according to the norms and values of the particular social group in question. Hardey (1998: cited in Burr, 2003) states that illness is about a person's reactions to symptoms, rather than the symptoms themselves, because if someone continues to perform their usual activities they are not considered ill. Thus, Burr (2003) asserts that defining pathology is a social matter, as illness only occurs when a person is constrained to live in an environment to suit the needs and activities of others. As Parker (1995), among others (Johnstone, 2000, Rogers & Pilgrim, 2005), has expressed, frequently those found to be mentally ill are the marginalised groups in society. It is often possible to describe the psychiatric population in terms of race, gender and class, so being

black, a woman or from a working class background immediately increases the chance of an individual being construed as mentally ill. Furthermore, some opponents of psychopathology suggest that it is a form of social control (Boyle, 1990, Johnstone, 2000) and serves many different interests including commercial, political, capitalist and psychiatrists (Rogers & Pilgrim, 2005).

Thus when considering how psychopathology is construed in adult and older adult mental health, one should take into account how it is construed generally. Given the critique of DSM-IV, it is pertinent to reflect if other ways of conceptualising mental distress are more helpful. Formulation focuses on an individuals' whole experience and thus is unique to each person. Throughout the essay the advantages of formulation will be discussed in light of the limitations of DSM-IV.

The issue of ageism

In terms of mental health in the UK, adults are defined as 18yrs -65yrs (working age) and older adults as 65yrs+ (retired and hence no longer economically productive). This speaks volumes about how Western society views age and the importance placed on the life course construction. The tripartite life course includes preparation and education, family building and work, then retirement (Riley & Riley, 1994: cited in Hagestad & Uhlenberg, 2005). Chronological age is a culturally bound way of construing individuals in industrialised societies but is not used in non-industrialised societies (Keith *et al.*, 1994: cited in Hagestad & Uhlenberg, 2005). This leads to the question; is this way of construing useful? Hagestad and Uhlenberg (2005) argue that segregating individuals by age leads to ageism which is linked to a negative view of our future selves. Furthermore, creating a dichotomy of adult age increases language signifying 'otherness' and so increases distinctions of 'us' and 'them' (Bytheway, 1995). Isolation, passivity and discontinuity in old age are seen as some of the consequences of privileging the tripartite life course (Riley and Riley, 2000: cited in Hagestad & Uhlenberg, 2005). Separating individuals by social policies and practises reduces cross-age interactions and promotes the development of age stereotypes; Allport (1954: cited in Hagestad & Uhlenberg, 2005) argues that a 'key weapon' against stereotypes and prejudices is inter-group contact by integration. Hence in terms of reducing ageism it may be more useful to have services that are not defined by age.

Graham (2003: cited in Werner, 2005) talks of older adults with mental disorders carrying a 'double burden' for being old and mentally ill. In support of this, the national director of older people's services, Ian Philp (2005), recognises there is age discrimination in mental health services and older adults have not benefited from service developments like adults have. He argues that services should be available on the basis of need, not age, yet also supports specialist services for older adults. Thus it seems age is far from being disregarded as a useful way of construing difference, despite lack of research or a theoretical model for separating services (Tindall & Manthorpe, 1997).

Categorising individuals by age has similar drawbacks to categorising them on the basis of their mental health difficulties. Older adults and adults is a problematic construction as it forces people into a dichotomy, insists on distinct difference rather than accepting variations on a continuum and, as discussed, leads to discrimination. Evidently the disadvantages of this come sharply into focus as the boundaries are approached. Differentiating between people on the basis of age supports the idea that people over 65 are different to those under. If retired people really do have different needs, should those taking early retirement access older adult services? Likewise, with the government increasingly supporting continued employment beyond 65, should those working after 65 access adult services? In what way does retirement make such a difference to mental health? It seems natural there will be differences in the mental health problems of adults and older adults, given the importance placed on age, as differences are likely to be emphasised and similarities suppressed, in line with the ageist view society endorses. This essay will consider whether those differences relate to the general construction of being an older adult, as opposed to differences in mental distress, and whether categorisation based on age or diagnosis is useful.

Overall, are difficulties in older adults less prevalent?

One commonly viewed difference in adult and older adult mental health is that difficulties are less prevalent in older adults, with the exception of dementia and sometimes depression. Despite this traditional lore (Palmer, Jeste & Sheikh, 1997), there are relatively few studies that focus on the prevalence of mental illness in older adult populations (Hybels & Blazer, 2003: cited in Jeste, Blazer & First, 2005). The epidemiological studies

focusing on older adult populations report a general trend of lower prevalence rates (Flint, 1994; Livingstone & Hinchcliffe, 1993). However, there are number of potential explanations for this, one being that DSM-IV is based on research into adult populations, hence prevalence differences may simply be an artefact of a categorical system only designed to recognise adult difficulties. Jeste and colleagues (2005) argue that problems in older adults are overlooked, misdiagnosed and mistreated as a result of these inappropriate diagnostic criteria.

There is an alarming lack of research into older adult populations. This is evident when carrying out literature searches and the paucity of research is a complaint echoed by many researchers focusing on older adult populations (Agronin & Maletta, 2000; Gallo & Lebowitz, 1999; Jeste *et al.*, 2005; Palmer *et al.*, 1997). This research void may signify that older adults are less valued compared with the employable population (Rogers & Pilgrim, 2005), and raises the possibility that research interests are affected by ageism. A number of researchers are anticipating a dramatic rise in the prevalence of problems in older adults once the first ‘baby boomers’ turn 65yrs in 2011 (Palmer, Heaton & Jeste, 1999; Patterson & Jeste, 1999). It is hoped that the increase in the size of the older adult population, and consequent demand in mental health services, will spur more interest in this population leading to more recognition and research.

A number of methodological factors have been raised, regarding how representative the results are in studies including older adults. For example, in the Epidemiological Catchment Area studies, public housing was under sampled, which is often where older adults with mental illness reside (Rabins, Black & German, 1996: cited in Palmer *et al.*, 1999) and socially isolated individuals are likely to have been underrepresented (Woods, 1999). Earlier editions of DSM used in prevalence studies have not included late-onset disorders such as schizophrenia and, hence, categories have been overlooked (Palmer *et al.*, 1997). Furthermore, researchers have queried whether self-reports are valid as a method of identifying mental illness. In older adult populations under-reporting of symptoms is more likely due to shame and perceived social inappropriateness of describing psychological and interpersonal difficulties (Wiener *et al.*, 1997). This is particularly relevant for the current cohort as they were raised in an era when mental illness had a tremendous social stigma (Agronin & Maletta, 2000). Self report is also not

ideal for diagnoses as it has been found there is low reliability when individuals recall remote episodes of psychiatric disorders (Simon & Vornkoff, 1995: cited in Agronin & Maletta, 2000).

One reported difficulty in diagnosing mental disorders in older adults is the higher chance there will be comorbid physical health problems. In the case of anxiety, diagnostic criteria require that physiological effects are not attributable to a medical condition. This makes it hard to decide whether anxiety is present as often the physiological symptoms of anxiety are also present in medical conditions such as hyperthyroidism and cardiac arrhythmias (Palmer *et al.*, 1997). Over the counter medications, which are reportedly used more by older adult populations, can have anxiety as a side-effect and anxiety might reflect the physiological reaction to the onset of a major medical problem (Palmer *et al.*, 1997). Depression is frequently comorbid with physical health conditions such as heart attacks (Blazer, 2000), diabetes (Blazer, Moody-Ayers, Craft-Morgan & Burchett, 2002), hip fractures (Magaziner, Simonsick & Kashner, 1990: cited in Jeste *et al.*, 2005) and strokes (Robinson & Price, 1982: cited in Jeste *et al.*, 2005). It has been linked to adjusting to changed circumstances brought on by physical health problems (Jeste *et al.*, 2005). A pertinent question is whether physical and psychiatric comorbidity is unique to the older adult population or whether it is seen throughout adulthood. Hays and colleagues (1997) report that the odds of physical comorbidity were nearly twice as high in chronically depressed members of their sample which included adults aged 18-90. There was no age effect when they compared the under 60's to those above, suggesting that comorbidity of physical health problems and depression is independent of age. One association found to be age dependent was physical impairment, which was only associated with younger adults. Hays and colleagues posit that cultural expectations for older adults allow for some functional impairment, whereas expectations for younger adults are based around physical functioning. Thus, whilst physical health problems may be more likely in older adults, the association between physical health problems and mental distress is also observed in adults and maybe more likely in terms of physical impairment. What is more, poor health and disability are not inevitable in older age and the majority of older people are illness free at any given time (Green, Monahan & Coleman, 1992: cited in Clarke, 2005).

The diagnostic criteria for mental disorders do not encompass age related changes in behaviour. In the case of anxiety, it may be harder to recognise in older adult populations as decreased physical abilities may play a role, avoiding going out at night may be due to visual problems being exacerbated (Jeste *et al.*, 2005). Perceptions about normal ageing may also hinder the recognition of anxiety disorders, new-onset agoraphobia may be attributed to an individual being less mobile and hence leaving their home less frequently (Palmer *et al.*, 1997). For substance misuse, the DSM-IV criteria refer to failure to fulfil major role obligations such as poor work performance, expulsion from school and neglect of children, none of which may be applicable to an older adult population (Jeste *et al.*, 2005). Further criteria are increased use and tolerance to a substance, however in older adults pharmacokinetic and physiological changes can alter drug tolerance, so that less consumption may have the same intoxicating effect (Patterson & Jeste, 1999). In the case of depression one criterion for diagnosis is changes in sleep pattern, again this may not be useful in older adults as often sleep changes accompany the ageing process (Woods, 1999).

To avoid obscuring difficulties in older adults, some individuals have called for separate categories, as is the case for children and adolescents (Agronin & Maletta, 2000; Jeste *et al.*, 2005). This would correspond with the dominant view in society of a tripartite life course. Perhaps the failings of DSM-IV to incorporate age related behaviour changes reflects the sole reliance on adult orientated research. It would be inappropriate to decide whether older adult categories are necessary on such a limited research base. The first step towards rectifying this problem would be conducting longitudinal research focusing on older adult samples. Conversely this presents a problem with circularity, which is inherent in DSM-IV, as to know how to change the criteria you need to study older adults with mental disorders, and to identify them you need to use the existing criteria. Diagnosing older adults seems harder due to their perceived complexity and the constraints of matching individuals to specific criteria. In contrast, a formulation approach allows individual complexities to be considered.

If you're an older adult, there must be an organic cause!

When considering older adult mental health, it is commonly construed that difficulties will relate to organic problems. Alzheimer's or severe memory problems are seen by the lay public as an inevitable part of normal ageing (Werner, 2005). Dementia is often viewed as

tragic, as it is not seen as a failure to cope or a result of personal inadequacy, neither is it linked to perceptions of madness or anti-social behaviour (Walton & Roques, 1994: cited in Tindall, & Manthorpe, 1997). Tragic is, in many ways, how old age is viewed by society in general. However the salience of dementia and biological causes may be overstated, as Kitwood (1988: cited in Rogers & Pilgrim, 2005) asserted, Alzheimer's disease can only be properly diagnosed post-mortem and this does not always show what is expected. Some individuals with confusion and memory impairments show no neurological signs and others with no signs of dementia show neurological deterioration. Livingston and Hinchliffe (1993) report that the prevalence of dementia is 5% in older adults, increasing to 20% in the over 80s. This means that a substantial proportion of older adults do not experience dementia. Furthermore, whilst organic causes are mostly construed as a phenomenon in older adults alone, this is not the case as early onset dementia occurs in adult mental health. It is estimated by the Newcastle Alzheimer's Society (1996: cited in Tindall & Manthorpe, 1997) that 22,000 people in the UK have early onset dementia (not connected to Down's syndrome or AIDS) and, in an average health district of 60,000 45-64yr olds there will be 20 people with early onset dementia (Newens, Forster, Kirkup, Bates & Edwardson, 1993: cited in Tindall & Manthorpe, 1997). In Leeds, at a given point in time, there were 132 individuals under 65 with identified dementia (Williams, Cameron & Deardon, 2001).

There has been international recognition for the different implications of dementia depending on time of onset (Tindall & Manthorpe, 1997). It is postulated that early onset dementia prevents 'age appropriate' activities such as employment, family care-giving, domestic activities and driving (O'Neill, 1992). Yet is this simply ageism at work? Hockey and James (1993) state that there are implicit assumptions about older people having fewer social roles, anticipating poor health and disability and society expecting child-like behaviour. Thus, when families and carers want specialist services for adults with early onset dementia separate from older adults (Furst & Sperlinger, 1993: cited in Tindall & Manthorpe, 1997) it may be the most negative aspects and fears about older age surfacing (Biggs, 1993). Given the negative consequences of separating individuals on an age basis, a specialist dementia service with a lifespan approach may be more useful than either separate services, or older adult services that accommodate adults.

A retrospective study identified it was easier to collect early onset dementia data as case records and investigations were more thorough than for older adult dementia (Whalley *et al.*, 1993). Similarly, Rana, Kerr and St Clair (1993) report that psychiatrists have a tendency to look for organic illnesses in older people, so biases operate in identifying difficulties because of the differences in constructions.

Depression, loss and social isolation

Between 13-16% of older adults in the UK are reported to experience depression (Copeland *et al.*, 1987; Livingston, Hawkins, Graham, Blizard & Mann, 1990), supposedly often due to social isolation, loneliness and adverse life events such as loss. This leads to the view that depression is an understandable part of ageing as opposed to a treatable condition which would be assumed with adults (McCrae *et al.*, 2005). One study proposes that older adults internalise their devalued status and accept persistent sadness uncritically (McCrae *et al.*, 2005), hence ageism prevents them seeking help.

Despite the common view that loss leads to depression in older adults, some research suggests fewer older adults than adults have severe grief reactions (McKiernan, 1996). Death is perhaps seen as more timely in later life, with emphasis placed on 'living with it' rather than 'getting over it'. Vanderhorst and McLaren (2005) found a lack of social support was associated with, and predictive of, depression in an older population. Moreover, individuals working in social care with older adults view social isolation as a key factor in depression (McCrae *et al.*, 2005). However, the link between social support and depression in older adults is not clear cut. It has been suggested that dimensions of togetherness, which encompass more than just social support, in particular a lack of guidance, are associated with depression in older adults (Tikkainen & Heikkinen, 2005). Although, there is insufficient evidence for a firm judgement, it seems reasonable to conclude that depression in older adults is often associated with perceived positions in social relationships. Blazer (2005) states there is 'a clear but not obvious relationship' between depression and social support in late life. Loneliness too is often assumed to be part of being older adult, but more than half an older adult sample of 973 reported they were not lonely at all (Victor, Scambler, Bowling & Bond, 2005). These factors do seem to be associated with depression, but not to the extent generally assumed.

Much the same pattern can be seen in the adult population, where a sense of belonging is negatively associated with and predictive of depression (Hagerty & Williams, 1999). Furthermore, loneliness and depression have been reported in similar rates in both adult and older adult populations (Tikkainen and Heikkinen, 2005). Research actually highlights that social support from family and partners is more important for younger adults' well being, although support and companionship with friends is beneficial throughout the lifespan (Segrin, 2003). Thus it would appear that social isolation is a significant contributing factor in adult mental health too and not only experienced by older adults. An individual's ability to cope with life seems more related to their developmental stage and not determined by age. Formulation approaches allow for the developmental stage to be considered whereas a diagnosis approach does not.

The importance of life stages

The importance placed on retirement means less emphasis is given to the impact of other life stages and transitions. Research suggests that unscheduled major life events (divorce, job loss) have a more deleterious effect on mental health than scheduled events such as retirement (Wheaton, 1990). The more predictable an event is, the easier it is to cope. It would appear role history, prior to transition, impacts on the stressfulness of an event, such that retirement, divorce and job loss can be positive in difficult situations. Identity salience is also important, with transitions being more stressful for those whose self worth is connected to their previous role. In the case of retirement, 30% of retirees report it as stressful (Bosse, Spiro & Kressin, 1996), yet two-thirds of workers find employment stressful. When considering other transitions a clear impact on mental health can be seen. In the case of having children there is a three fold increase in the onset of depression five weeks following birth (Cox, 1993), with the prevalence of post-natal depression estimated at 13% (O'Hara & Sullivan, 1996). The impact of life stages will depend on an individual's ability to adapt to changing circumstances, this is not age related. Thus it is clear that the emphasis placed on the importance of retirement over and above other life transitions is unwarranted.

Moreover, the assumption that older adults are a homogenous group in terms of their developmental stage and the transitions they encounter has been called into question. Neugarten (1982) states that older adults are more heterogeneous than young and middle

aged adult populations. Erikson's eight stage theory of psychosocial development (1963), was recently revised (1998: cited in Brown & Lewis, 2003) to incorporate a ninth stage. Older adulthood being no longer solely focused on the psychosocial crisis of integrity versus despair, but moving on to gero-transcendence, where there is a shifting of perspective to looking beyond the self. There has been some preliminary research to confirm the existence of a ninth stage of psychosocial development (Brown & Lewis, 2003), which means that if psychopathology were to be construed differently in terms of life stages then both older adults and adults should each be separated into two groups. Yet this seems nonsensical, perhaps adulthood should not be divided at all and adults and older adults should be considered as one, with the developmental stage always being considered relevant, as it will have importance throughout adulthood and not just at retirement.

Implications for practice

Current services are organised in line with the dominant psychiatric view of psychopathology, with diagnosis and medication at the forefront. An implication for practice is that disorders, other than dementia or depression, are less likely to be recognised in older adults. This narrow focus gives rise to concern as it can lead to apathy in diagnosis and therapeutic nihilism (Crosby, 1997: cited in Clarke, 2005). It is more likely that older adults will be given medication (Lindesay, 1991, McKenzie & Marks, 1997) and not offered therapeutic interventions (Koder, Brodaty & Anstey, 1996). If older adults are offered a therapeutic service, these are not sufficiently resourced to provide for all those in need (Banjeree, 1998). Thus the effect of the current situation in older adult mental health is, in the main, quite negative.

Yet, older adults may benefit from the more cautious approach when considering their difficulties. In practice, fewer axis II diagnoses are assigned to older adult patients as compared to adult patients, yet it is estimated 60% of older adults with mood disorders fulfil comorbid personality disorder criteria (Molinari, Ames & Essa, 1994: cited in Hillman, Stricker & Zweig, 1997). Instead of defining older adults by DSM-IV, clinicians may be more likely to consider the complexities of their difficulties and formulate their problems in context. Whereas formulation is less likely to be used for adults, as they fall more easily into DSM-IV categories. This is a disadvantage as contexts and developmental life stages are not considered.

At the very beginning of a career in clinical psychology, I have already witnessed the importance of issues relating to retirement and ageing for an individual's view of themselves, yet this has occurred in an adult mental health setting. This illustrates the caution that should be exercised when assuming life stages occur in line with a fixed chronological timetable.

Case example: A 57yr old woman presenting with health anxiety, depression and hoarding behaviour. The issues are longstanding; however her current preoccupations are very interlinked with facing issues of physical health problems in terms of her husband and caring for her parents. Current challenges for her include adjusting to retirement, the ageing process and renegotiating how she evaluates herself in light of her changed circumstances.

This demonstrates that many issues construed as common to older adults are also present in the adult population. Of the five adults I have begun individual work with so far, central to the formulation of three is the impact of stopping work. Hence it seems apparent that separating services on the basis of age will not lead to different problems being encountered in different settings. One study focused on the effect of different ages (46, 66 and 86) on decisions made by psychologists when presented with identical clinical vignettes. For the vignette of the 86yr old, age salient characteristics were more likely to be identified such as increased suicide risk, likelihood of hospitalisation and suitability for ECT treatment (Hillman et al., 1997). Dementia, organic causes and the need for medical examinations were also more likely to be considered. Whilst these are construed as markers of good practice, they could also be applicable at 46 and 66. Staying alert to the importance of developmental life stages, comorbid physical conditions and cognitive impairment are essential at any age. All adults should be treated the same, and given the climate of ageism, maybe the only way to overcome discrepancies is to integrate services.

Conclusion

Differences in the construction of psychopathology between adults and older adults seem linked with the cultural view of old age as a time of decline. There is a general lack of research into older adult mental health, reflecting the ageism that is present in society,

categorising older adults as less important than adults of employable age. Healthcare practices currently endorse this ageism by separating services for adults and older adults on the basis of this despite no theory or research supporting such a division. Whilst older adults' psychopathology is seen as less prevalent, there are many reasons why this may not be the case. Based on the limited research there is, it appears as if adults and older adults are more similar than different. Differences seen are due to the biases in where attention is focused. Organic causes are not isolated to the older adult population, nor are social isolation and loss as factors associated with depression. Similarly, life transitions are important throughout adulthood and retirement plays no more of a role in difficulties than other major life transitions. The cumulative effect of the ageist lens used in the construction of psychopathology is that older adults lose out compared to adults. They are less likely to be recognised as having treatable difficulties and are less likely to be offered non-pharmacological treatments. Ageism seems to be at the root of much of the differences seen and the separation of services. Until research is more focused on older adults and the cultural, social and political influences in constructions of psychopathology are considered, construing adults as different after 65 will remain questionable.

It appears DSM-IV has many limitations, categorising individuals by a descriptive system overlooks the context of problems, and indicates neither cause nor solutions. An alternative way of construing difficulties is by using a formulation approach. This focuses on an individual's experience; it encapsulates the whole context, seeks to explain why difficulties have occurred, and thus indicates possible solutions. It allows complexities and developmental stages to be considered and does not assume differences on the basis of age. Mental health problems occur as a result of how people cope with life; formulation offers a way of uncovering this and diagnostic labels do not. A formulation approach is beneficial for all, it does not categorise individuals hence eliminating the need for separate services for adults and older adults.

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WRITTEN EXERCISE 2

Prime Minister Tony Blair recently announced that families struggling with unruly children will be provided with compulsory parenting courses along with “super-nannies”. These child psychologists will be deployed to “problem areas” in the Government’s latest attempt to boost family life. Discuss this initiative critically. Do you think that “super-nannies” know best?

Cassie Bromley

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Year 2

5047 words

The RESPECT initiative

Compulsory parenting courses and ‘super-nannies’ are to be introduced across the UK as part of the government RESPECT initiative aimed at reducing anti-social behaviour (BBC News, 2006). It was reported 77 ‘problem’ areas would be given funding to employ child psychologists to provide parenting courses, intensive work with families, liaison with professional networks and advice to Family Intervention Project workers (BBC News, 2006). Parenting orders will be used to enforce these interventions if children have broken the law or refused to attend school. Since the first announcement the Home Office has clarified the ‘super-nanny’ positions will be open to any parenting experts, not psychologists, as the jobs are more general than just psychological (Jarrett, 2007). This is important as there may be large differences between what psychologists offer, due to the broad range of theory they can draw upon to inform formulation and interventions, and those specialising in parenting alone. It also highlights an immediate dilemma; as without clarity, about the professions involved, evaluating this initiative is difficult.

I intend to review the effectiveness of parenting courses, the implications of this initiative and consider the broader context with alternative perspectives for ‘unruly children’. The reason I am reviewing parenting courses and not ‘super-nannies’ is due to the lack of clarity about ‘super-nannies’. The concept first arose from the popular ‘super-nanny’ television series, on this basis it is likely ‘super-nannies’ will use similar interventions as parenting courses, although on a more intensive individual basis. I am influenced by both social constructionist and constructivist ideas and hence have chosen to consider the influence of dominant societal discourses around the construction of ‘unruly children’ and ‘struggling families’. From this position there is no objective truth or reality outside of history, culture and social processes, which serve to privilege some patterns of social action whilst excluding others (Gergen, 1985, cited in Burr, 2003).

Do parenting courses work?

The recent government publication on preventing anti-social behaviour and crime (Sutton, Utting & Farrington, 2004) highlighted ‘The Incredible Years’ (Webster Stratton, 1992), ‘Triple P Positive Parenting Program’ (Sanders, 1999) and ‘Living With Children’ (Patterson, 1975) as the three most researched parenting programmes available. All three are social-cognitive behavioural approaches, extensively researched over the last 30 years,

with well established effectiveness (Hutchings, 2005). Based on social learning theory and the assumption children learn to relate to others through social interactions within the family, these approaches use modelling, positive reinforcement, time out and contingency contracting to increase pro-social cooperative behaviour and decrease unwanted behaviour (Kazdin, 1993).

The 'Living with Children' programme (Patterson, 1975), was established first and, although not used much within the UK, it influenced the development of many other programmes. In the UK the most widely used is 'The Incredible Years' (Webster Stratton, 1992), a 12 session group programme for parents of children up to 8 years, using video clips, group discussion and home tasks to build a strong positive relationship between parent and child, which is seen as the foundation of effective discipline. There are also teacher and child programmes that can run alongside or independently from the parent programme and an advanced programme for parents of children up to 10 (Webster-Stratton, Reid & Hammond, 2001). The Triple P Positive Parenting Program (Sanders, 1999) is an Australian multi-system intervention of 5 levels of increasing intensity. These range from a universal population level, in which awareness of parenting resources, receptivity to parenting programmes and optimism of solutions are increased through the media, to intensive individually tailored behavioural family intervention programmes. The programmes work on creating a safe, engaging and positive learning environment, using assertive discipline, having realistic expectations and parents taking care of themselves.

Studies have consistently demonstrated parenting programmes can result in the long-term reduction of behaviour problems (Hutchings, 2005; Sanders, Markie-Dadds & Turner, 2003). Moreover, high levels of acceptability and parent satisfaction are reported (Sanders *et al.*, 2003; Webster-Stratton, 1989). Research indicates programmes are most successful for children up to 8 and require specific and common therapy factors, highly skilled facilitators and programme fidelity (Sutton *et al.*, 2004). The focus of programmes is primarily preventive, teaching principles rather than specific techniques, so protective factors associated with severe behavioural and emotional problems are increased and risk factors decreased (Sanders *et al.*, 2003). Factors considered important in interventions are empowering families, building on existing strengths and developing good therapeutic relationships (Sanders & Ralph, 2004). Also important, are goals addressing risk factors,

accessibility, developmental and cultural appropriateness, a family focus and scientifically validated theory base (Sanders & Ralph, 2004).

What if the child is over 8?

Research clearly indicates programmes are more effective if difficulties are tackled early, with success decreasing with a child's age (Hutchings & Webster-Stratton, 2004). Conduct disorder in older children is viewed as harder to change. Behaviour is embedded in a broader range of rewarding systems such as family, peer group, school and community, so contingencies in all systems need to alter for an effective intervention (Lynam *et al.*, 2000). Moreover, conduct disorder in adolescence often occurs alongside secondary risk factors like academic failure, school drop-out and deviant peer group affiliation (Ruma, Burke & Thompson, 1996). The proposed initiative does not specify an age range; many children are likely to be older than the parenting programmes' target age range as conduct disorder is more prevalent in secondary than primary school children (Meltzer, Gatwood, Goodman & Ford, 2000). Moreover, by the time parenting orders are considered, it is likely the behaviours will have been present for some time; hence the appropriateness of a preventive intervention developed for young children is questionable. With older children and young adolescents more intensive interventions involving family and multi-systemic therapy or even, treatment foster care, are recommended (Carr, 2006).

The myth of 'hard to reach' families

It is commonly reported family interventions are hard to implement; often those most in need being hardest to reach (Sutton *et al.*, 2004). Risk factors for children's problem behaviour are also risk factors for poor treatment outcomes (Dumas & Wahler, 1983). Programmes are often ineffective if there is extreme socio-economic disadvantage, maternal depression, conflict between partners, a single parent or social isolation (Hutchings & Webster-Stratton, 2004). Recruitment rates from low income families are low and they are more likely to drop out, relapse or not make clinically significant improvements (Wahler, Cartor, Fleischman & Lambert, 1993, cited in Hutchings & Webster-Stratton, 2004). Typically research trials demonstrating parenting programmes' effectiveness are based on volunteers or people selected by referrers as willing to participate, thus excluding many disorganised, unmotivated or disadvantaged families (Scott, Spender, Doolan, Jacobs & Aspland, 2001).

One view is good behavioural programmes often fail to reach the most vulnerable parents because low self-esteem and negative experiences of being parented makes parents doubly anxious and defensive. Hyper-vigilance to criticism can mean even valuable advice is taken by parents to imply they were doing it wrong before (Puckering, 2004). Consequently many of the neediest do not seek referrals or accept help from services as they are perceived as stigmatising and inaccessible (Hutchings & Webster-Stratton, 2004). Furthermore, parenting courses are criticised as having unrealistic expectations, failing to understand family circumstances, where time pressure, childcare and resource limitations mean many parents cannot consistently attend (Timimi, 2005). Thus, there is a growing consensus parenting interventions have been ‘unreachable’ rather than families (Webster-Stratton & Hooven, 1998). This more hopeful position suggests if issues of engaging disadvantaged families are addressed and services made accessible there is no association with disadvantage and outcome (Baydar, Reid & Webster-Stratton, 2003). This is an important shift in thinking, as services traditionally assume if a family truly desired change they would seek help, which ignores the multiple barriers families have to overcome in order to access help (Snell-Johns, Mendez & Smith, 2004). Suggested solutions include offering transportation, child-care, self-directed learning and making initial contact by telephone (Snell-Johns *et al.*, 2004).

This view is supported by Hartman and colleagues (Hartman, Stage & Webster-Stratton, 2003) who found depression, stress and socio-economic status did not significantly contribute to outcome following parenting interventions for child conduct problems. Similarly, in preventive parenting programmes run at Head Start centres in the USA, maternal risk factors such as mental health problems, being abused as a child and substance abuse did not affect the engagement or gains made by mothers attending compared to controls (Baydar *et al.*, 2003). Interestingly, parents with more negative and ineffective parenting prior to programmes were more engaged (Baydar *et al.*, 2003) and mothers perceiving their children as more problematic were keener to participate (Reid, Webster-Stratton & Baydar, 2004), dispelling the myth that those most in need are hardest to reach.

In the UK, when offered to parents of children aged 3- 8 referred to CAMHS with anti-social behaviour, 'The Incredible Years' resulted in a large reduction in anti-social behaviour in contrast to a control, (Scott *et al.*, 2001). Parents were from poor and disadvantaged circumstances and the children were considered at high risk of juvenile delinquency and social exclusion. A crèche, good quality refreshments and transport were provided and recruitment and attendance were good (Scott *et al.*, 2001). Similar positive results have been found with courses run for disadvantaged families in community settings by the voluntary sector (Gardner & Burton, 2003).

The 'Mellow Parenting' course (Puckering *et al.*, 1994; 1996) was specifically developed for parents with a background of abuse, neglect, being in care or mental health problems. Lasting 14 weeks, on a day a week basis, it offers psychotherapeutic support, video and hands-on practice, with high engagement and success (Puckering *et al.*, 1994; 1996). Engagement is encouraged through offering transport, childcare and a pleasant welcoming environment, lunch is shared between staff, parents and children and opportunities are created for parents to have fun with their children. Thus it appears efforts to engage families considered disadvantaged are successful if the support offered works to overcome access barriers.

Cultural sensitivity

The majority of parents accessing parenting courses in the UK are white middle-class women (Smith, 1996). This is unsurprising considering parent training was developed with intact, middle-class white families in mind, based on the assumption particular behaviours, such as positive reinforcement and non-physical punishment are best (Kotchick, Shaffer, Dorsey & Forehand, 2004). Hence a criticism of parenting courses is their lack of cultural sensitivity. Timimi (2005) argues, because parenting courses are only as good as the philosophy underlying the approach, their lack of multi-cultural awareness often results in failed attempts to impose an unacknowledged white middle-class Western value system onto alienated sections of the community. There is more than one way to parent, different cultures conceptualise childhood differently and this is reflected in parenting practices. With little known about what is effective with different groups, sensitivity to expectations, attitudes and practices is crucial (Kotchick *et al.*, 2004).

‘The Incredible Years’ claims to foster cultural sensitivity by parents identifying their own goals for their children, thus respecting diverse viewpoints (Reid, Webster-Stratton & Beauchaine, 2001). African American, Asian American, Caucasian and Hispanic mothers of children recruited to ‘The Incredible Years’ through Head Start were equally likely to attend, make positive long-term changes and report high levels of satisfaction with the programme (Reid *et al.*, 2001). However, differences were seen in recruitment, with minority families less likely to join. This is consistent with other literature (Harachi, Catalano & Hawkins, 1997) and suggests, although parenting interventions may be effective with different cultural groups, more effort is needed to engage minority families and ensure recruitment strategies are culturally sensitive (Reid *et al.*, 2001). Furthermore, the differential engagement from minority families limits the generalisability of surmising parenting interventions are equally effective across ethnic groups, as it may not be so for those choosing not to engage.

The importance of formulation

Parenting interventions are not always effective, with one third of children remaining in the clinical range for problem behaviour at follow-up assessments (Hartman *et al.*, 2003). This suggests the factors influencing anti-social behaviour are more complex than parenting alone, highlighting the importance of assessment and formulation. Even supporters of parenting interventions are clear they should not be automatically offered as the only intervention for anti-social behaviour (Scott *et al.*, 2001). Offering parenting interventions for every child presenting with anti-social behaviour without understanding their presenting difficulties, the predisposing, precipitating and maintaining factors, is inappropriate. It is like assuming prescribing anti-depressants to all adults with depression will be helpful. There may be a multitude of factors associated with the behaviours, and complex formulations are common for conduct disorder as children often come from multi-problem families (Carr, 2006). Understanding the personal meaning and social context of difficulties within a whole person, whole system framework, is key to helping people (Johnstone, 2000), but the RESPECT initiative appears to assume the same interventions will be helpful for all.

The underlying message

The proliferation of parenting programmes and advice has been coined by Furedi (2001) as the ‘professionalisation’ of parenting, which he argues treats all parents as potential failures, instead of the small minority needing help. The populist view is irresponsible parenting is to blame for youth crime (Utting & Pugh, 2004). This is disempowering to parents, as not only does it ignore the wider social issues contributing to youth crime and anti-social behaviour, it locates blame with parents, sending the message they are not competent and need an expert to show them how to parent. This can be seen in the language used; with words such as ‘super-nanny’ implying ‘good enough parenting’ is no longer adequate. The impact of this can be understood through relational frame theory, which proposes that once verbal relations are made they never seem to go away, hence problems are created and maintained through relational frames of language (Hayes, Strosahl & Wilson, 1999). The media further fuels this; exposing dysfunctional parenting models, rather than celebrating strong models of parenting and family (Long & Hoghughi, 2004). The problematic nature of the narrow ‘prescriptive and military’ view of parenting offered is highlighted by Dr. Tanya Byron, a clinical psychologist and popular TV parenting figure, who warns the idea there is a ‘right way’ to parent is de-skilling (Raising kids, 2007). Successful parenting interventions rely on collaboration, giving back dignity, respect and self-control to parents, who may have low confidence and feel guilty (Baydar *et al.*, 2003). The importance of therapists not being positioned as experts dispensing advice and lectures is continually emphasized (Webster-Stratton & Herbert, 1994). Consequently, whilst the government attempts to ‘boost family life’ with offering ‘experts’, the factors interventions seek to enhance, such as parent confidence and self-esteem, are undermined.

This lack of understanding for the consequences of supposedly well-intentioned initiatives is illustrated by Anti-Social Behaviour Orders (ASBOs). Introduced in 1998, for the same purpose as this new initiative, ASBOs are aimed at reducing anti-social behaviour. Of the ASBOs granted between April 1999 and September 2001, the majority (74%) were for people under 21, with a significant portion (36%) breached within 9 months and on multiple occasions (Campbell, 2002a; 2002b). Moreover, it is suggested that ASBOs are now perceived as a ‘badge of honour’, which Smith (cited in BBC News, 2006) describes as understandable because of the recognition they give offenders, which is often lacking in

their lives. Hence, it appears ASBOs, although introduced as a deterrent, offer some positive reinforcement. Just as the ‘super-nanny’ initiative aims to empower parents, it may serve to have the opposite effect. In a review of what really works with anti-social behaviour, Nacro concluded a holistic approach is needed, as focusing on one intervention alone only results in a quick fix at the expense of long-term solutions (Armitage, 2002). Yet it seems as if the ‘super-nanny’ initiative has not heeded this recommendation, as it implies parenting interventions are the only intervention needed. This focus on parenting is troubling, as families do not develop independently of the prevailing culture and this focus loses sight of the wider ecological perspective (Long & Houghugh, 2004).

The impact of compulsory interventions

A major concern regarding the government initiative is the issue of compulsion versus consent. Consent is pivotal in psychological interventions, as interventions aim to empower individuals. The impact on the therapeutic relationship when interventions are compulsory needs consideration, as the most reliable and robust finding in psychotherapy research is a good therapeutic alliance is the best predictor of outcome (Horvath & Symonds, 1991). If parents are forced to attend a course or accept help the therapeutic alliance will not start from a collaborative base and motivation to engage is likely to be low (Puckering, 2004). A person’s motivation to change is vital to successful psychological intervention (DiClemente, Bellino, & Neavins, 1999), therefore, ordering someone to attend a parenting course is likely to be ineffective at producing change. Moreover, when support is initiated by official agencies in response to a problem, rather than self-initiated, the support is viewed as stressful and does not provide the supportive scaffolding needed to enhance the efforts of highly stressed families (Kotchick *et al.*, 2004). Whilst research demonstrates the effectiveness of interventions with highly stressed families, it is in community based programmes where participation is voluntary (Reid *et al.*, 2004; Scott *et al.*, 2001). To my knowledge, there is no research exploring the effectiveness of enforced parenting interventions. However, the RESPECT coordinator claims enforced parenting courses are equally as effective as voluntary courses (BBC News, 2006), but it is unclear what research this refers to.

Reviewing the literature in other areas where compulsory interventions are used shows mixed results about the impact. Whilst in drug and alcohol research no differences are seen

between the effectiveness of voluntary and involuntary interventions (Gregoire & Burke, 2003), involuntary mental health inpatients are less engaged with interventions and have more symptoms at discharge compared to voluntary inpatients (Craw & Compton, 2006). In eating disorders, research indicates there are no differences in the short-term effectiveness of interventions (Watson, Bowers & Andersen 2000; Ramsey, Ward, Treasure & Russell, 1999), but long-term outcomes for involuntary patients are less positive (Ramsey *et al.*, 1999). Whilst these findings may bear no direct relevance on parenting interventions, they do highlight that assuming enforced interventions will be as effective as voluntary interventions is problematic.

The context

Conduct disorder is seen as a growing problem, with 7.4% of boys and 3.2% of girls reported to meet diagnostic criteria in the UK (Meltzer *et al.*, 2000). Some claim this is unsurprising in a capitalist society that promotes narcissism and discourages deep interpersonal attachments (Dwivedi, 1996); others have explored systemic issues such as the corrosive impact of poverty and social changes (Hoghughi, 2004). The UNICEF report into childhood well-being ranked the UK as the worst place to grow up out of 21 economically advanced countries, based on material well-being, health and safety, education, behaviours and risks, family and peer relationships, and subjective well-being (UNICEF, 2007). Over 15% of UK children grow up in relative poverty, which is persistently related to a number of negative outcomes, including poorer health, learning and behaviour difficulties, underachievement, teenage pregnancy and unemployment (UNICEF, 2007). The link between poverty, parenting and outcomes for children is seen as obvious yet complex; it is difficult to disentangle whether poor parenting or poverty are causes or effects, but it is clear a 'cycle of disadvantage' occurs (Puckering, 2004). Even the best parental efforts can be compromised by poverty, with its daily struggles, low expectations and erosion of hope; many propose without simultaneously tackling family poverty, its correlates and consequences, no society can hope to promote better parenting (Hoghughi, 2004; Bandak, 2005).

Long and Hoghughi (2004) identify many social changes impacting on parenting and conclude it is illogical to blame parents for all child problems as parenting influence is limited. The rapidity of social change means 21st century parenting is a different task to

previous generations (Utting & Pugh, 2004). Fewer marriages, increased co-habitation, high teenage birth rate, higher divorce rate, lone parent families and the growing divide between rich and poor are some of the changes cited (Utting & Pugh, 2004). In addition, the shift from multi-generational to individual family units has led to greater isolation and decreasing practical and emotional support available to parents (Long & Hoghughi, 2004). Parents are also spending more time working to provide basic necessities, so children's emotional needs are given less time, leaving parents increasingly disengaged from their children (Long & Hoghughi, 2004). Etzioni (1993) argues this combination of relationship breakdown and work pressure is leading to the neglect of children's needs. However, government policy actively supports parents working, offering incentives such as more affordable childcare and training, with work viewed as the best route out of poverty, taking precedence over children's needs (Utting & Pugh, 2004).

Children grow up in the value system of their culture; in the UK a capitalist value system operates with freedom and self-gratification at the centre. In many ways those behaving anti-socially are adopting the culture's capitalist values, whereby self-worth and power are achieved through self-gratification with theft, drugs, alcohol and violence (Timimi, 2005). Gangs can be likened to mini-capitalist cultures with the most self-serving the most admired (Timimi, 2005). In this culture of competition, boys are more often losers than winners at school (Arnot, David & Weiner, cited in Timimi, 2005), and may turn to macho subculture to defy the system hurting them. Frosh, Phoenix and Pattman (2002) argue the construction of masculinity is part of the problem, discursively produced and reproduced as a cultural phenomenon; it embodies a lack of recognition experienced by young males in British society. The narrow possibilities available of acceptable masculinities and the view young men are social problems which society has to manage and control is often internalised and reproduced, with a vicious cycle of delinquency emerging as a way of expressing the anger felt towards a society that has written them off (Frosh *et al.*, 2002). In this sense, boys seek refuge in the 'hardness' of hegemonic masculinity in response to the perception they are problematic.

Ideas of normal and deviant childhood change over time as a result of changing political and social circumstances (Timimi, 2005). The current vision of childhood in the West is ambivalent, and polarised, between victimised innocents needing rescuing and impulsive,

aggressive, sexual beings threatening society (Timimi, 2005). Timimi (2005) argues behind the polarisation is the suggestion society has seen a collapse in adult authority, such that pressure is put on parents and schools, and the perceived blame for things going wrong is diverted onto the child. In effect children become scapegoats, with society's fear of impending chaos projected onto them. Psychodynamic theory can help with understanding this process, as the more society buys into capitalist values, the more the social conscience generates guilt, causing anxiety which is projected into a scapegoat as a defence. Hence a paranoid-schizoid reaction occurs, in which a blame culture emerges where groups are targeted to carry the collective burden of guilt, because of the culture's inability to tolerate risk and anxiety (Timimi, 2005).

From this formulation, society can be viewed as dealing with guilt and anxiety through cultural defence mechanisms such as social services, CAMHS and parenting classes, targeting the blame for failure on children and parents (Timimi, 2002). Hence children become seen as 'unruly', with 'parenting' at fault. The government's new initiative is perhaps an attempt to be seen to be doing something, in response to this paranoid schizoid view. Yet, in reality, the being seen to do something appears to take precedence over the doing. My experience of the NHS is despite clear evidence and guidance supporting preventive services (Sutton *et al.*, 2004), they are the first to go in a climate of cuts. On my CAMHS placement there was no funding for work with children under 10 referred with behavioural problems and direct work in the tier 2 'preventive' service was cut. Moreover, Sure Start, aimed at providing comprehensive support services to families with children under 4 living in disadvantaged neighbourhoods, in reality only reaches one third of the population defined as in need (Utting & Pugh, 2004). Thus there seems to be a gap between what the government promotes and where resources are directed.

Alternative ways forward

Community psychology

As the social and cultural context is recognised as having a substantial influence on parenting, community psychology seems an appropriate alternative to parenting courses. Community psychology is concerned with understanding people in the context of their communities; exploring transactions between social setting and person (Orford, 1992, cited in Harris, 2005). It seeks to prevent problems of living, celebrate human diversity and

pursue social justice through social action (Nelson & Prilleltensky, 2005). Whilst the therapeutic relationship is heralded as important in therapeutic outcomes, approximately 40% of outcome variance is determined by environment (Lambert, 1992), hence the importance of environment should not be overlooked. The Family Well-being Project (FWP) (Harris, 2005) and Sutton Hill Families Project (Bandak, 2005) are examples of community psychology in action. In the FWP a community psychologist provides services for children and families in a community regeneration context (Harris, 2005). Accessibility is maximised by offering a self-referral drop-in service within a local primary school, with referrals often concerning parenting. Analysis of micro-referral patterns highlighted the housing problems of those most in need. From this many hypotheses were generated; the hard-to-let nature of the housing indicated desperation in those accepting it, the barrack-like rows of housing and secluded alleyways meant behaviour was difficult to supervise and manage and the lack of play facilities or communal areas prevented a sense of community developing. These significant environmental effects indicated community development and housing services were more appropriate than psychology for individual families, and hence other organisations were engaged to offer support, preventing stigma and child blaming in the families living there (Harris, 2005). The Sutton Hill Families Project took a community approach by running workshops around the concerns identified by families referred for parenting (Bandak, 2005). Often families' first concern was debt, establishing their own agenda was empowering, resulting in high attendance and support for each other, which is suggested as the first step towards community building (Bandak, 2005).

Changing social discourses

Another way forward would be society accepting that children do not grow up independent of culture and hence moving from a position of child-blaming to a more complex understanding of the interplay between social and cultural forces on young people. The media and government have an important role to play, as, whilst they recognise poverty and a lack of social support are problematic for families, often this thinking is not taken forward when considering 'unruly children'. Expanding the limited social discourses around childhood would help to move from this discursively produced phenomenon (Frosh *et al.*, 2002) and offer young people more opportunities to develop to their potential. The negative impact of limited discourses for young men was demonstrated in Frosh and

colleagues' (2002) research, wherein boys balanced their ambition to succeed at school with the sanctions and ostracism of not fulfilling the 'masculine' stereotype. This struggle for young people was illustrated during my CAMHS placement by a 16 year old male I worked with. Referred for panic attacks, central to his difficulties was a fear of rejection, such that he became anxious in social situations. He worried about the public perceiving him as 'rude' because of his age, believing society viewed young people as 'disrespectful' which he attempted to challenge by ensuring he was always extremely polite. His sensitivity to others perceiving him negatively, led to him ruminating about situations in which he felt he had been thoughtless. His anxiety in anticipation of social situations resulted in worries about how others would perceive him if he was anxious, which he thought of as 'unmanly' and hence a vicious cycle was created. Thus it seems moving away from a modernist view, which assumes there is one true way of viewing young people, such as they are 'unruly', to a post-modernist view, in which many different alternative views can be held simultaneously, would be beneficial.

Where are the fathers?

What is striking in parenting literature is whilst families are often referred to, the research usually only includes mothers (Reid *et al.*, 2004, Scott *et al.*, 2001). With fathers in Britain working the longest hours in the EU and an increase in lone-parent families (Utting & Pugh) the responsibility for child rearing usually falls on the mother (Timimi, 2005). The absence of fathers is commonly noted in CAMHS' settings too, and fitted my experience of children often being brought to appointments by their mothers. The importance of father involvement cannot be understated, with research highlighting their role in infant development (Lamb, 1997, cited in Roggman, Boyce, Cook & Cook, 2002) and young people voicing their disappointment when there is a lack of emotional involvement with their fathers (Frosh *et al.*, 2002). Some research has begun to explore characteristics influencing father engagement with parenting interventions (Roggman *et al.*, 2002); however this is a relatively new area as interventions traditionally target mothers. If families are offered support it is crucial the whole family is included; this may require flexibility and creativity to overcome the barriers to engaging fathers.

Conclusion

Parenting interventions can be effective, but cultural sensitivity, awareness of their decreasing effectiveness with age and accessibility are key factors to consider. Collaboration is vital; hence compulsory interventions seem, at best, misguided and, at worst, detrimental due to the underlying message they portray. Enforcing interventions implies parenting requires 'experts', thus disempowering and undermining parents' self-esteem, diametrically opposing the aim of parenting interventions. Assuming one intervention will benefit all is simplistic; formulation should be at the foundation of supporting others as this enables the whole system to be considered. Emphasis on parenting alone ignores the social factors influencing child behaviour, such as poverty, isolation and cultural values. Emphasis on 'faulty parenting' can be understood within a psychodynamic framework as a defence against society's guilt for the negative consequences of an individualistic and self-gratifying value system on children. Alternative ways forward from the professionalisation of parenting and scapegoating of children could be accepting responsibility for the social and cultural impact on children. A community psychology approach working with people in context, the introduction of positive discourses about children, a widening of discourses of masculinity and greater emphasis on the role of fathers, all could offer positive alternatives to compulsory parenting courses and 'super-nannies', achieving the government's aim of 'boosting family-life'.

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SMALL SCALE SERVICE RELATED PROJECT

A service evaluation examining the demand in a secondary level adult community psychology service and the implications of reconfiguring the service to increase accessibility.

Cassie Bromley

April 2007

Year 2

5043 words

Abstract

This study examined the local needs of individuals accessing an adult community psychology service, using a cross sectional view of those waiting for the service. This service mapping exercise aimed to gather a better understanding of how the service was operating and the local differences in need. The results showed 163 individuals were waiting to access the service, with the majority (131) waiting for the stand-alone service. The different levels of demand resulted in varying waiting times across the service, with the stand-alone bases accruing the longest and the South-East and West areas producing the biggest relative need. Individuals waiting for the CMHT service were more likely to have two or more presenting problems than those waiting for stand-alone psychology (62.5% and 38.2% respectively). Social phobia and bipolar were more prevalent in the CMHT service, in comparison the stand-alone service had a higher percentage of individuals with depression, obsessive compulsive disorder and post traumatic stress disorder, however the proportions differed between areas.

The second part of the study explored the effect on estimated waiting times of improving access to the stand-alone service by devolving it to local CMHT areas. Waiting times varied according to the resource deployment criteria used; relative need proved the most promising. The proposed advantages and disadvantages of reconfiguration demonstrated the complex implications involved, reinforcing the need for clear rationale when considering service restructuring. In conclusion this project highlighted the need for the service to continue tracking demand and individuals' needs and keep systematic waiting time information for all parts of the service. The results provided a useful starting point to inform future service development, whilst emphasising the necessity for longitudinal data too.

Introduction

Since 2004, the government has awarded Foundation Trust status to some National Health Service Trusts. Foundation Trusts are set up in law under the *Health and Social Care (Community Health and Standards) Act* (UK Department of Health, 2003) as legally independent organisations called public benefit corporations. They continue to be part of the NHS providing care according to NHS quality standards and principles; free care based on need, not ability to pay. However, they are accountable to local people and have new financial freedoms, the key advantage being they are free from central government control to develop services to suit the needs of the local community (Department of Health, 2005). This fits with the government's agenda of a patient-led NHS, as set out in the NHS Improvement Plan (Department of Health, 2004).

Over recent years there has been recognition of the increasing demand for psychological therapies. The Department of Health's guidance on '*Organising and Delivering Psychological Therapies*' (2004) states that 'psychological therapies should no longer be regarded as optional' and 'access to effective psychological therapies should not be constrained by the vagaries of local geography and history' (p.3). Accordingly, the configuration of how psychology services are provided is important, with government policy supporting improved access. The guidance defines improved access in terms of location, timing, co-ordination within the system and mode of delivery and asserts that local commissioners and employers need to be flexible to match services to local needs and resources. This service evaluation focuses on both location and timing.

For location, it recommends psychological therapies are provided in locally available GP surgeries, community centres or clinics with good transport links. In my experience clients often endorse this by stating their preference to be seen in a location nearer their home.

Long waiting times are a key concern highlighted by both service users and carers (*Organising and Delivering Psychological Therapies, 2004*). The Department of Health recommends the target of a 3 month maximum wait for outpatient appointments in planned care (*Improvement, Expansion & Reform: The Next Three Years, 2002*). There is currently no specific information about waiting times for psychological therapy, but the Healthcare Commission hope to develop a trust performance indicator in the future. The waiting time

for the stand-alone psychology service is increasing with demand and, in line with the government's recommendations, the service is under pressure to reduce waiting times.

Aims of the service evaluation:

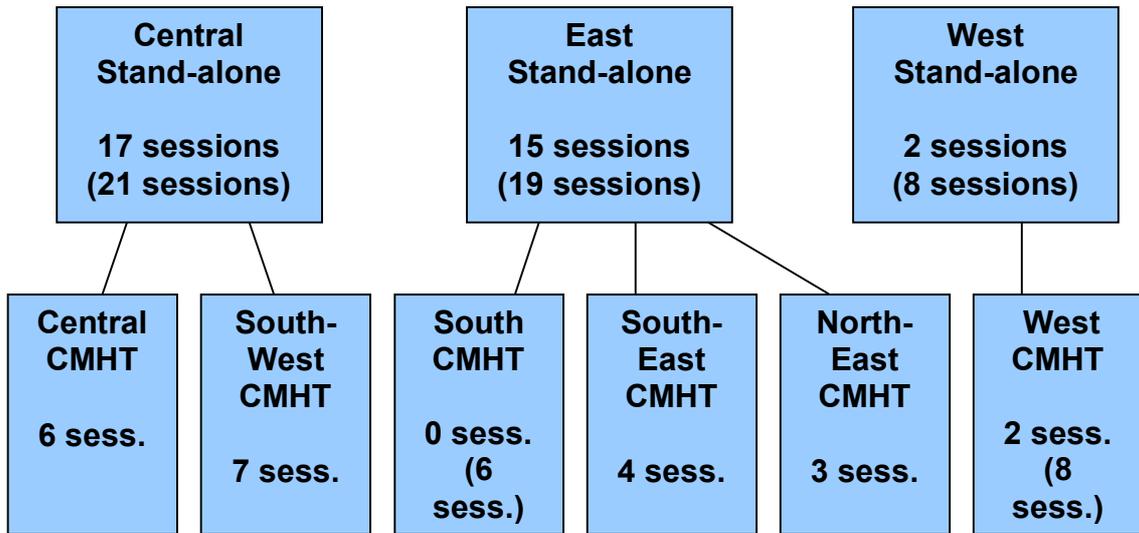
There were two main aims for this service evaluation. Firstly, in line with the government's agenda to create a needs based NHS, one aim was to provide information about the local needs of individuals waiting for individual therapy from the adult community psychology service. This is of particular importance as it gives a better understanding of how the service is operating and what the unmet needs are, which is crucial when considering issues around service development. The second aim was to investigate the implications on waiting times if the adult community psychology service was reconfigured to improve accessibility (in terms of location). This was a hypothetical exercise to explore the issues around reconfiguration and the possible effects.

Service description

The adult community psychology service is part of a newly appointed Mental Health Foundation Trust. The Trust covers a large geographical region, with both rural and urban areas. It has an adult population of approximately 430,000, who are predominately white British and of mixed socio-economic circumstances. The adult community psychology service currently consists of 3 stand-alone bases and 6 community mental health team (CMHT) bases (see figure 1). Individuals referred to the stand-alone psychology service will be seen in the base nearest to where they live, which could be over 12 miles away. In contrast, individuals seen in the CMHT will be seen by the team in their local geographical area.

Figure 1

Current Configuration of the Adult Community Psychology Service



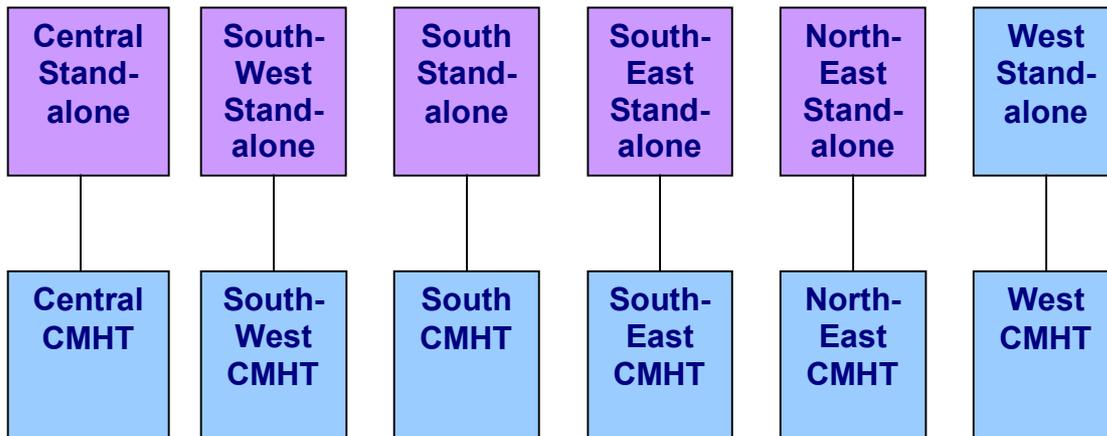
(Bracketed number of sessions = number of sessions if vacancies filled)

— Lines denote which CMHT services are in which stand-alone base area.

The proposed reconfiguration as identified by the Head of Service, would involve the stand-alone psychology service being devolved to the local areas covered by the CMHTs (see figure 2). This would allow individuals for the stand-alone service to be seen locally at the CMHT clinics, hence improving accessibility.

Figure 2

Proposed reconfiguration of Adult Community Psychology Service



Lines denote which services cover the same geographical area



= Change to current service

Project questions:

Stage One:

- What are the current waiting times in each part of the service?
- How many clients awaiting stand-alone psychology are from each CMHT area?
- Are there are areas of greater or lesser need relative to the population?
- What are the referred mental health problems of clients awaiting CMHT and stand-alone services as a whole and in each CMHT area?

Stage Two:

- If reconfigured how many sessions would be allocated to each part of the service and what impact would it have on waiting times?
- What resource deficits are highlighted based on the reconfiguration?
- What are the advantages and disadvantages of the proposed reconfiguration?

Method

Design

This service evaluation had a cross sectional design and focused on all individuals waiting for individual sessions from the adult community psychology service at the beginning of August 2006.

Data source

-Referral information

As stated above, the data source comprised all clients on the individual treatment waiting lists at the beginning of August 2006. The information regarding these individuals was held separately for each part of the service, either by the psychologist in the CMHT or the team administrators in the stand-alone service. Information was collated on a database from each individual's paper file (i.e. part of service waiting for, gender, age, referrer, referral problem and CMHT area). The information needed to determine which CMHT area individuals on the stand-alone waiting list belonged to differed according to each area. For example, in the Central stand-alone area, the CMHT areas were defined by the street where they lived, whereas in the East stand-alone area the CMHT areas were defined by their GP surgeries.

-Waiting times

The data available on waiting times for each part of the service varied across areas. Where possible, data on the waiting times for individuals using the service since July 2005 were used, as was the case for the Central and East stand-alone bases. If past information was unavailable the waiting times for the current caseload in each part of the service were identified, as was the case in all the CMHT bases except the West. In the West part of the service (both stand-alone and CMHT) there had been a change in staff and no current caseload was in operation, hence the waiting times of the previous psychologist's last month's caseload were used.

-Team discussion

Possible advantages and disadvantages of service reconfiguration were identified during a team discussion and a record kept of the points raised.

Analysis

Descriptive statistics were used to examine all questions in stage one of the project.

In stage 2, the deployment of resources for the proposed reconfigured stand-alone service were based on various factors identified in collaboration with the Head of Service and were as follows:

- 1) Resources allocated based on current practice
- 2) Resources allocated based on population size
- 3) Resources allocated based on current demand
- 4) Resources needed to achieve a 12 week waiting time

To determine the effect on waiting times for each resource deployment criterion, ratios were calculated on the basis the current waiting time for each part of the service sustained a current waiting list based on the current resources available i.e. Number of people waiting for service/ Number of sessions available to service is proportional to the number of weeks' wait (see appendix 1 for a worked example).

Ethical Considerations

The service evaluation was limited to reviewing waiting list information already held by the service. Although this was collated onto a new database, the anonymity of individuals was ensured by assigning a code to each person. Access to the database was restricted to the project collaborators; hence confidentiality and data protection legislation were adhered to.

After consultation with the Trust's Research Governance Steering Group, this study was classed as a service evaluation and approved by the Trust. As the project was classed as a service evaluation, obtaining ethical approval was unnecessary (COREC Ethics Consultation E-group, 2006).

Results

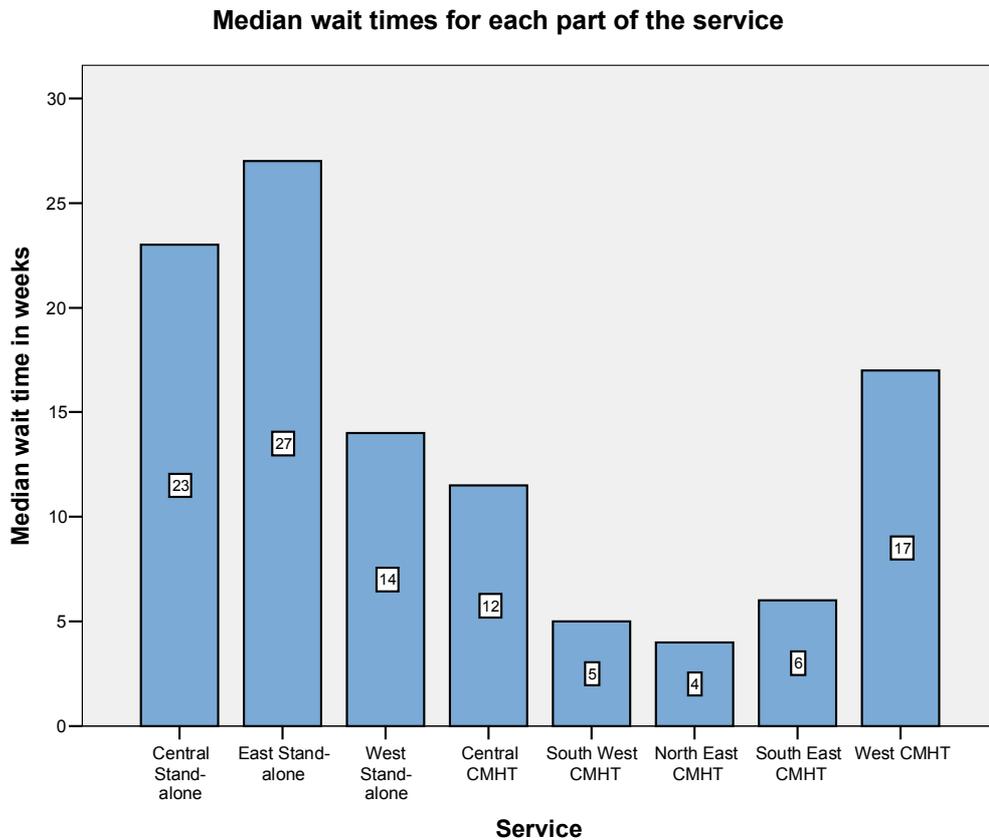
General description of individuals waiting for the psychology service

At the beginning of August 2006, 163 people were waiting for the psychology service, 131 were waiting for the stand-alone service and 32 for the CMHT service. Of those waiting 58% were female and 42% were male and these proportions remained similar when looking at each part of the service. Ages ranged from 18 to 65 and the mean age was 40. All individuals waiting for a CMHT service were referred by a member of the CMHT, as expected. Of those waiting for a stand-alone service, the majority were referred by psychiatry (52.7%), with the clinical assessment service also referring a substantial proportion (24.4%) (See appendix 2 for further information).

Current waiting times in each part of the service

As can be seen in figure 3 the median waiting times calculated for the different parts of the service varied from 4 weeks in the North-East CMHT to 27 weeks in the East stand-alone base. The median waiting times were used for comparison as they are more robust statistics when there are outliers or extreme cases in the distributions, as was so with the South-West, North-East and South-East CMHTs. As discussed in the data source section, different methods were used to calculate the waiting times depending on the data available, consequently some of the figures are more accurate than others. For example, waiting times for the West region, where there was no psychologist, were calculated on the previous psychologist's last month's caseload. This may not be representative of a normal caseload, plus there was a large amount of missing data (no information on 16 clients), hence it is advisable to treat the figures for the West stand-alone and CMHT tentatively. There is no data on the South CMHT because there was no service in operation there. Moreover, as the Central and South-West CMHTs are more established than the North-East and South-East CMHTs, they may experience more demand which would influence the waiting times. Overall, it appears there was a longer wait for the stand-alone service than CMHT.

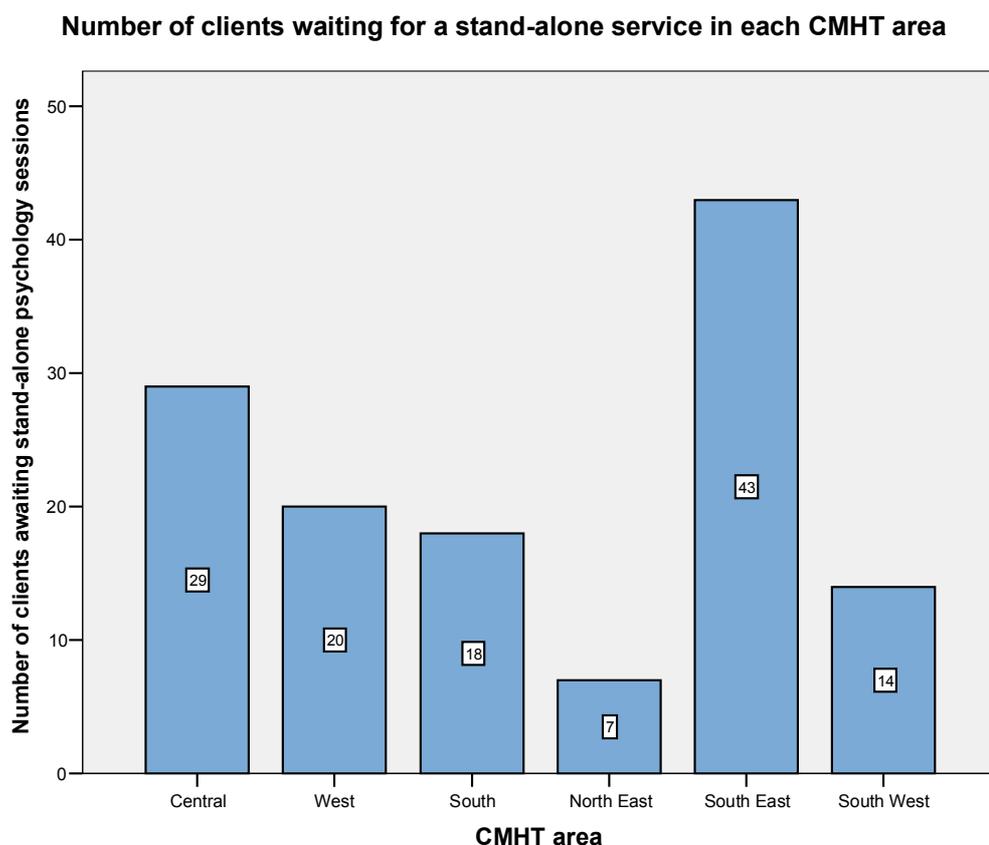
Figure 3



Number of clients awaiting stand-alone psychology in each CMHT area

Of the 131 clients waiting for stand-alone psychology across the whole geographical area, 43 were from the South-East (32.8%), 29 from Central (22.1%), 20 from West (15.2%), 18 from South (13.7%), 14 from South-West (10.6%) and 7 from North-East (5.3%) (See figure 4). This suggests there are large differences in the number awaiting stand-alone psychology from each area, with the South-East producing the biggest demand and the North-East the least.

Figure 4

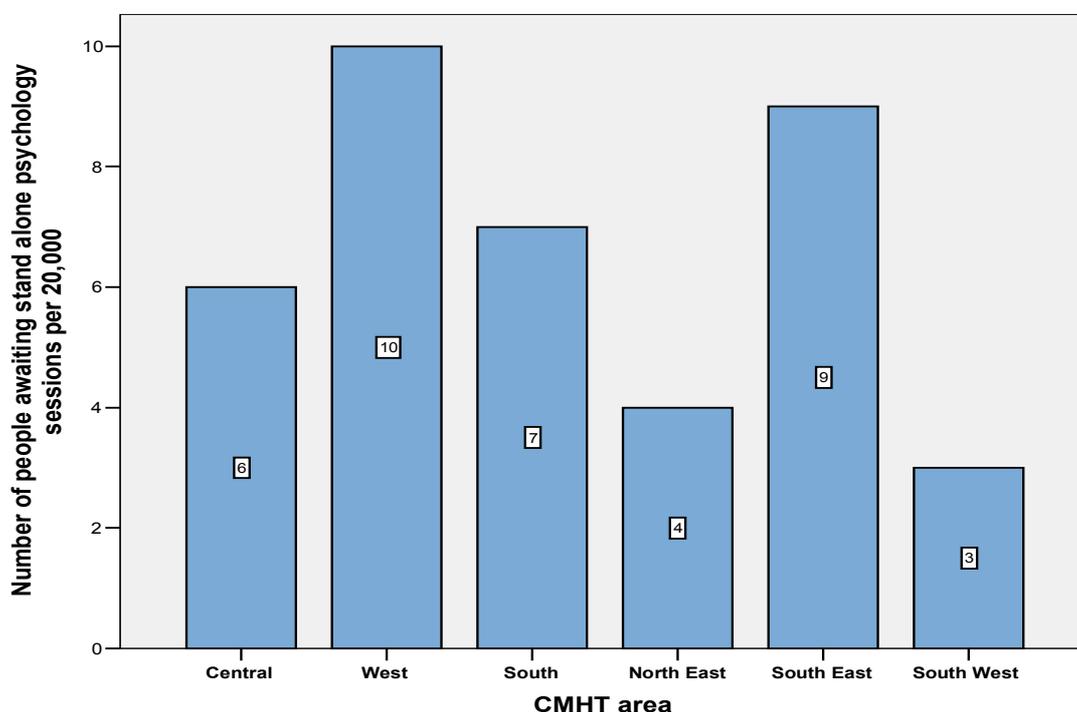


Areas of greater or lesser need relative to the population

On looking at the number of people awaiting stand-alone psychology in each CMHT area relative to the population size of the area (as defined by National Statistics, 2006), a different picture was seen (see figure 5). Whilst the South-East did seem to produce more demand for stand-alone psychology (9 per 20,000 people waiting for a service) than other areas, the area with the highest demand was the West (10 per 20,000 people). Moreover, whilst the North-East seemed to produce less demand than other areas (4 per 20,000 people), the area producing the least demand was the South-West (3 per 20,000 people). Statistical analysis to determine whether these differences in relative demand were significant was not appropriate due to the large margin of error with such small figures; therefore definite conclusions cannot be drawn.

Figure 5

Areas of greater or lesser need relative to the population size for each CMHT area



Mental Health Problems referred

CMHT services

Table 1 displays the main presenting problems of the 32 individuals awaiting a CMHT service. Ten of them (31.2%) had one identified presenting problem, 20 (62.5%) had two or more and there was missing data on 2 (6.3%).

Table 1

Main Presenting Problems of individuals awaiting a CMHT service

Main Presenting Problem	Frequency	Percent (%)
Depression	5	15.6
Social Phobia	4	12.5
Depression and Anxiety	3	9.4
Obsessive Compulsive Disorder	3	9.4
Bipolar disorder	3	9.4
Post Traumatic Stress Disorder	2	6.3
Personality Disorder	2	6.3

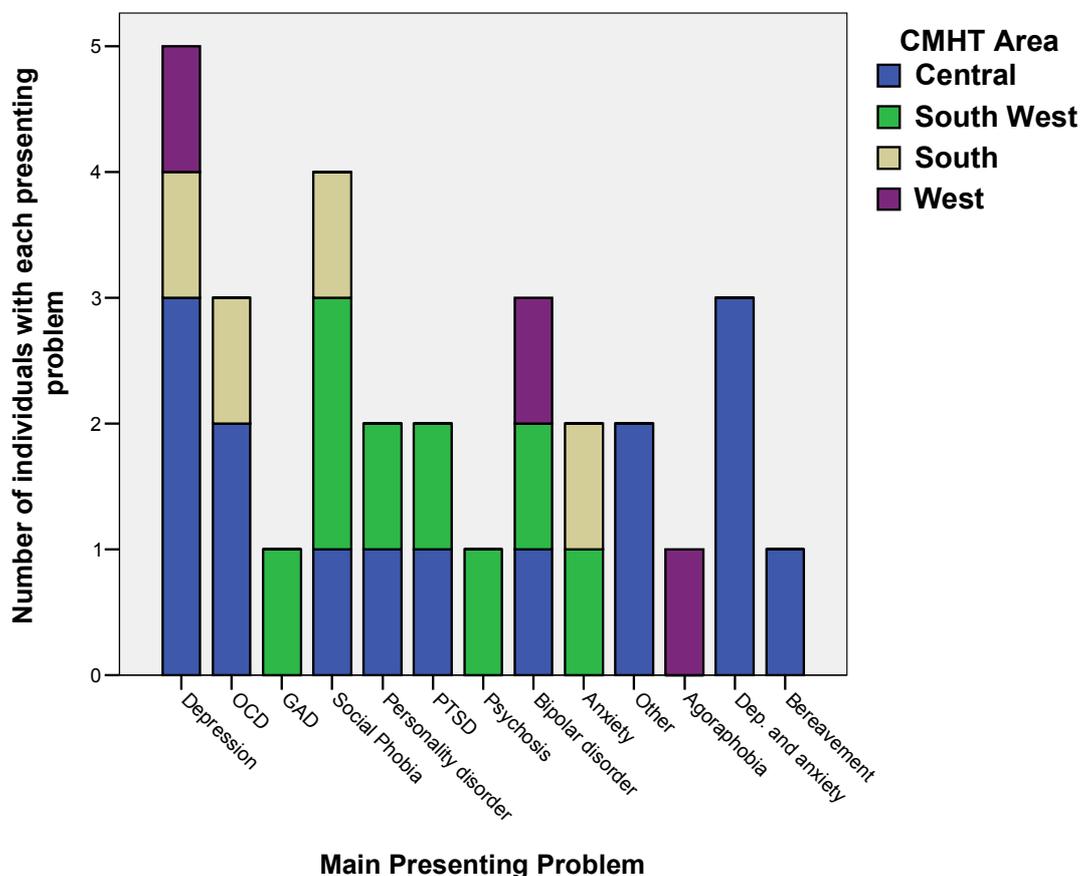
Anxiety	2	6.3
Other	2	6.3
Bereavement	1	3.1
Psychosis	1	3.1
Generalised Anxiety Disorder	1	3.1
Agoraphobia	1	3.1
Missing	2	6.3
Total	32	100

Depression, social phobia, depression and anxiety, obsessive compulsive disorder (OCD) and bipolar disorder were the most common presenting problems of individuals awaiting a CMHT service, accounting for more than half. Psychosis, bereavement, generalised anxiety disorder (GAD) and agoraphobia were the least common. The classification was biased by the referral information available, thus individuals classified as presenting with depression and anxiety might have met the criteria of specific anxiety disorders, such as agoraphobia or GAD.

The following graph (figure 6) shows the main presenting problems of individuals awaiting a CMHT service in each area. There is no information regarding the North-East or South-East CMHT as there were no waiting lists in those areas. Due to the small number of people awaiting a CMHT service it is not possible to draw firm conclusions about trends as area differences may simply be a consequence of the small numbers. For example, it is only in the Central area that people have been referred for depression and anxiety, this may relate to different referral biases, less referral information being available to make a specific classification or reflect actual area differences. Overall, it seems in the areas where there are more people waiting there is a wider spectrum of presenting problems.

Figure 6

Main Presenting Problems of individuals waiting for a CMHT service in each area



Stand-alone services

Table 2 displays the main presenting problems of the 131 individuals awaiting stand-alone psychology. Eighty of them (61%) had one identified presenting problem, 50 (38.2%) had two or more and there was missing data for one (0.8%).

Table 2

Main Presenting Problems of individuals awaiting stand-alone psychology

Main Presenting Problem	Frequency	Percent (%)
Depression	31	23.7
Obsessive Compulsive Disorder	18	13.7
Post Traumatic Stress Disorder	14	10.7
Depression and Anxiety	11	8.4
Other	11	8.4

Depression with Panic Disorder	9	6.9
Bipolar Disorder	7	5.3
Anxiety	6	4.6
Panic Disorder	6	4.6
Anger Problems	3	2.3
Agoraphobia	3	2.3
Relationship Problems	2	1.5
Social Phobia	2	1.5
Simple Phobia	2	1.5
Generalised Anxiety Disorder	1	0.8
Personality Disorder	1	0.8
Anorexia Nervosa	1	0.8
Health Anxiety	1	0.8
Depression and Bulimia	1	0.8
Missing data	1	0.8
Total	131	100

Depression, OCD, post traumatic stress disorder (PTSD), depression and anxiety and ‘other’ were the most common presenting problems of individuals awaiting stand-alone psychology, representing over 60%. The category of ‘other’ included self-harm, less frequent problems such as trichotilomania and referrals where the problems were not clearly specified. GAD, personality disorder, anorexia nervosa, health anxiety and depression and bulimia were the least common. In comparison to the presenting problems in CMHTs, the most striking differences are the higher percentage of referrals for social phobia and bipolar disorder in CMHT services, and the higher percentage of referrals for PTSD, depression and OCD in stand-alone psychology.

The following graph and table (figure 7 and table 4) show the top seven main presenting problems of individuals awaiting stand-alone psychology by each area.

Figure 7

Main Presenting Problems of individuals waiting for a stand-alone service in each area

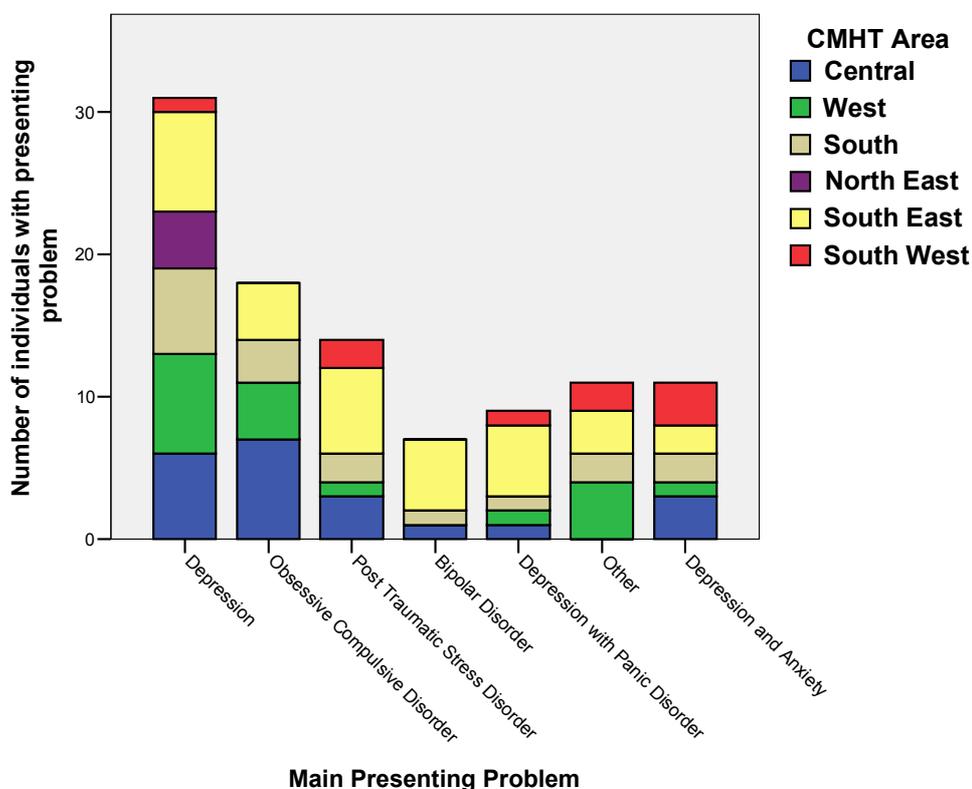


Table 4

Presenting problem	Percentage of individuals from each area with presenting problem						
	Whole region	West	South	North-East	South-East	South-West	Central
Depression	23.8%	35%	33.3%	57.1%	16.7%	7.1%	20.7%
OCD	13.8%	20%	16.7%	0%	9.5%	0%	24.1%
PTSD	10.8%	5%	11.1%	0%	14.3%	14.3%	10.3%
Bipolar	5.4%	0%	5.6%	0%	11.9%	0%	3.4%
Depression with panic disorder	6.9%	5%	5.6%	0%	11.9%	7.1%	3.4%
Other	8.5%	20%	11.1%	0%	7.1%	14.3%	0%
Depression and anxiety	8.5%	5%	11.1%	0%	4.8%	21.4%	10.3%

The North-East had the highest percentage of individuals awaiting psychology sessions for depression (57.1%), the South-West the least (7.1%). There were no individuals waiting from the North-East with the next 6 prevalent problems, however there were considerably

fewer individuals waiting from this area as a whole. OCD was particularly prevalent amongst individuals from the Central region (24.1%) and higher than those with depression (20.7%), whereas none of the individuals waiting for sessions from the North-East or South-West presented with OCD. PTSD was highest in the South-East and South-West (14.3% each) and bipolar disorder was also highest in the South-East (11.9%). The West area had the largest percentage of individuals (20%) with ‘other’ presenting problems, and the South-West the largest percentage of individuals with depression and anxiety (21.4%).

Reconfigurations

Table 5 displays how many sessions would be allocated to each part of the stand-alone service if it were reconfigured to increase accessibility and the resultant waiting times. There were 48 sessions available to stand-alone psychology, 14 of which were vacant. The first three proposed resource deployment criteria were based on the total number of sessions available remaining the same at 48. The last resource deployment criteria examined how many sessions would be needed in each part of the service to meet a maximum 12 week wait, provided no changes were made to how stand-alone psychology was delivered.

Table 5

The number of sessions available in the reconfigured stand-alone service and resulting waiting times based on different resource deployment criteria

Services		Central	South-West	South-East	North-East	South	West
Currently: Sessions/Waiting time in wks (If vacancies filled)		17/23 <i>(21/19)</i>		15/27 <i>(19/21)</i>			2/14 <i>(8/4)</i>
Reconfigurations	1) Same	14/19	7/18	12/21	2/21	5/21	8/4
	2) Population	12/22	10/13	11/23	4/10	6/18	5/6
	3) Current Demand	11/24	5/25	16/16	2/21	7/15	7/4
	4) Max. wait 12 weeks	22/12	11/12	22/12	4/12	9/12	2/12

Italics depict which figures need to be used extremely cautiously, due to the original waiting time estimate being less reliable. Consequently the West area is not referred to in the analysis below.

Depending on which resource deployment criteria are used, the resources indicated for each part of the service vary considerably. If the resources were deployed proportionally as they are currently allocated, the Central area followed by the South-East area would receive the most (14 and 12 sessions respectively). As expected, the waiting times would remain similar to the current situation, with only small differences across the region. Whilst the current provision could reflect differences in money available to different areas and the history of service development, it could also reflect differences in local need or indicate the consequences of supply and demand; when a service has resources the demand for it increases, but, when a service is under resourced, referrers refer people elsewhere.

If the resources are deployed based on population size, which assumes there is equal need in each area, then the Central, followed by the South-East and South-West areas would receive the most sessions (12, 11 and 10 respectively). This approach appears to increase the discrepancies between waiting times in each part of the service, with those in the Central and South-East areas having to wait considerably longer than those in the South-West or North-East (22 or 23 weeks compared with 13 or 10). Clearly, this resource deployment criterion is unacceptable as it does not improve equity in service access.

If the current demand criterion is used, the resources indicated for each area are quite different compared to when the population criterion is used, but less different to when the current practice criterion is used. Again the South-East and Central areas would acquire the most sessions (16 and 11 respectively) and the South-West and North-East the least (5 and 2 respectively). The waiting times would range from 15 to 25 weeks across the region.

When a maximum 12 week wait is set the resources needed to achieve it vary from 4 to 22 sessions across the region. In total it appears 68 sessions would be needed across the region to achieve a 12 week wait (not including the sessions required for the West). This is 20 sessions or 2 whole-time equivalents more than is currently available and suggests the service would need further resources to achieve a 12 week wait target.

Advantages and disadvantages

Listed below are some preliminary ideas about the potential advantages and disadvantages of deploying the stand-alone service to CMHT bases to improve accessibility for the community.

Advantages

- Improved accessibility
- Continuity across service levels
- Resource deficits highlighted

Disadvantages

- Isolates psychology team members
- Pragmatics- rooms, computer access, admin support
- Less choice of clinician

The main advantage was identified as improved accessibility for individuals who currently live far from the stand-alone psychology bases. With improved accessibility, one might expect individuals to use the service more, especially those without transport and those who have limited flexibility around the times they can attend sessions. A further advantage was seen as greater continuity between services for individuals who may be seen initially in the stand-alone service and then the CMHT and vice versa. This might also lead to improved communication across the service levels with other professionals, as there would be a clear link to the wider psychology team at each CMHT base. Another advantage identified was that it might help highlight resources deficits more clearly for commissioners and the public, as there would be an obvious picture of how many sessions were available in each part of the region and the corresponding waiting times, as opposed to the issue being harder to define due to the large areas being covered and fewer waiting lists.

One disadvantage of reconfiguring the stand-alone service was identified as isolating the psychology team members, as if they worked solely at the CMHT bases they would have little psychology team input outside of the formal arenas of supervision and team meetings. More pragmatic disadvantages were raised in terms of whether rooms and computer access would be available at the CMHT bases. Similarly, the administrative support, which is currently located in the stand-alone bases, may be less accessible if the service was reconfigured. The final disadvantage raised was the

decreased choice that would be available to individuals in terms of the clinician they see. Whilst stand-alone services are centrally based, individuals have the opportunity to select the gender of their clinician and a clinician's strengths can be matched to individual needs. However, if the service was devolved, there would be perhaps only one or two clinicians working in each area and hence the choice for individuals would be restricted.

Discussion

Summary of results

At the beginning of August 2006, 163 individuals were waiting for individual sessions from the adult community psychology service. The waiting times ranged from 4 to 27 weeks across the service, with the demand and waiting times for the stand-alone part of the service exceeding those for CMHT psychology. The relative need for the stand-alone service appeared to differ across the region, with the South-East and West areas creating the greatest demand and the North-East and South-West the least. Overall, the most common presenting problems of individuals waiting for a CMHT service were depression, social phobia, depression and anxiety, OCD and bipolar disorder with 62.5% presenting with two or more problems. The most common presenting problems of those waiting for a stand-alone service were depression, OCD, PTSD, depression and anxiety and 'other', with 38.2% presenting with two or more problems. There were area differences in terms of which were the most prevalent presenting problems, which might reflect differences in local referral patterns, epidemiology or chance.

With regards to the proposed reconfiguration to make the stand-alone service more accessible, it seemed the resulting waiting times for each area would differ considerably depending on the resource deployment criteria used. In terms of producing equity across the region the population criterion seemed particularly unhelpful, with large discrepancies in the estimated waiting times. This was not surprising in light of the apparent differences in relative need for stand-alone psychology across the region. Relative need was perhaps the most promising criterion for determining resource deployment, warranting further investigation. Moreover, it fits with the government agenda of developing services based on need (Organising and Delivering Psychological Therapies, 2004). Most striking was the extra resources

needed if waiting times were to be reduced to a maximum of 12 weeks across the region based on the service continuing to operate as it does currently. It was indicated at least 2 further whole-time equivalent psychologists would be needed, which highlighted the deficit of resources in the service. This need is supported by the Division of Clinical Psychology's (2006) recommendation of one whole-time equivalent psychologist per 30,000 individuals in adult services. This suggests around 14 whole-time equivalent clinical psychologists are needed for a population of approximately 430,000, whereas currently there are 8.2. In terms of advantages and disadvantages to reconfiguration the preliminary discussion raised some important points, such as pragmatics, restricted clinician choice and continuity across service levels, all of which would need much further consideration if the proposal were to be taken forward.

Methodological issues and limitations

The database created to collate information on individuals waiting for psychology sessions was thorough, as there was only limited missing data. This meant the results were representative of the current situation. Only one section of the database, presenting problems, required some clinical judgement as opposed to straightforward factual information gathering (such as gender, age and referrer). The categories used to describe the presenting problems were based on the descriptions used in the referral letters. Due to co-morbidity the categories were not discrete and some difficulties were experienced with categorisation particularly when there was co-morbidity or a lack of detail in the referral letters, which often resulted in the 'other' category being used.

The main methodological limitation was inherent in the cross sectional design, which restricted the generalisability of the findings. Taking a cross sectional view did not allow trends in presenting problems to be seen over time. Differences observed would have been influenced by referrer bias, for example some referrers may refer many individuals whilst others fewer and some may only refer particular presenting problems, whereas others may refer a wide spectrum. Trends in service demand were also not possible to gauge with a cross sectional view, some months may result in more referrals than others and demand from each area may differ over time. These factors need to be borne in mind when considering the results and the information

should be used tentatively. What the information gathered provided was a starting point for defining the service in terms of how it is currently operating, the differences and similarities, which could be expanded upon in the future.

A further limitation was the reliability of the waiting time estimates, as different data was available across the service hence different methods were used which would have introduced bias. It would be preferable to have the same information available for each part of the service and use the same method to calculate the waiting times; ideally this would be done longitudinally.

Due to the reconfiguration calculations being based on waiting times and current demand, and the aforementioned problems with both parts of these data, the results have to be used cautiously. However, the process was of clinical importance and served as a useful starting point to build on in the future.

Implications for the service and further research

This service evaluation provided a clearer picture of how the adult community psychology service was operating in August 2006 in terms of the demand and needs of those waiting for the service. It also examined what the implications of reconfiguring the service to increase accessibility might be. The results of the service evaluation were presented to and discussed with the team and Head of Service in September 2006. The Head of Service also requested a copy of the final report. The team were particularly interested in the following areas for future investigation; what the trends in demand and presenting problems were in each part of the service over time and the different referral patterns in each area. To help with this, it was acknowledged that information on waiting times needed to be kept systematically in all parts of the service, as opposed to just the Central and East stand-alone bases. It was felt that continuing to track the needs of those waiting for the psychology service would further enhance understanding of the needs of the local population and inform service development. This was considered necessary before further thought could be given to reconfiguration of the service. In conclusion this service evaluation was deemed to have been an important step in laying the foundation necessary before service development can be considered.

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Appendix 1

To calculate the estimated waiting times for each criterion of resource deployment ratios were calculated on the basis that the current waiting time for each part of the service sustained a current waiting list based on the current resources available i.e. Number of people waiting for service/ Number of sessions available to service is proportional to the number of weeks wait.

Worked example

The calculation below estimates the waiting time for the South-West stand-alone base if the resources deployed are kept in proportion to current practice i.e. 7 sessions are available out of the 17 that currently serve the Central region. The waiting list for stand-alone psychology consists of 14 individuals from the South-West area, out of a total of 43 individuals from the whole of the Central region. The current wait time for the Central region is 23 weeks.

$$\begin{aligned} \% \text{ demand} \div \% \text{ resources} &= \% \text{ wait time} \\ (14/43) \quad \div (7/17) &= \% \text{ of 23 weeks} \\ 0.326 \quad \div 0.412 &= 0.791 \times 23 \\ &= 18.19 \text{ weeks} \end{aligned}$$

If 7 sessions were available for the South-West stand-alone service the estimated waiting time would be 18 weeks.

Appendix 2

Referral source of individuals waiting for the stand-alone service

Referral source	Number of referrals	Percentage referred
Psychiatry	69	52.7%
Clinical Assessment Service	32	24.4%
Primary Care	11	8.4%
CMHT	9	6.9%
Resource Therapy	2	1.5%
Psychotherapy	2	1.5%
Other	3	2.3%
Missing	3	2.3%
Total	131	100%

A LITERATURE REVIEW

Experiences of children and adolescents living with a parent with mental health problems

Cassie Bromley

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Year 3

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Experiences of children and adolescents living with a parent with mental health problems

A Literature Review

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Introduction

The impact of parental mental health on children and parenting has received much attention over the years, yet surprisingly little is known about the experiences of children with parents with mental health problems. Taking a social constructionist approach, assuming the “map is not the territory” (Korzybski, 1973) and socio-cultural processes influence the versions of reality held, I am keen to consider areas yet to be explored. In this review I intend to define the current UK situation for children of parents with mental health problems and highlight why research in this area is important. I aim to describe and critique the main areas of research in this field before suggesting further areas warranting investigation. I reason the emerging qualitative research exploring families’ experiences, in particular those of children and young people, has a lot to offer our understanding. Moreover, I argue for a more positive focus moving away from the dominant risk burdened one, and also, the inclusion of fathers with mental health problems in research.

Children of parents with mental health problems

Prevalence

Whilst it is known ten percent of the adult population experience mental health problems at any one time, there is a lack of systematic data on the number of children growing up with parents with mental health problems (Falkov, 1998). This may result from Adult Mental Health and Child and Adolescent Mental Health Services having different focuses, neither emphasising adult mental health problems in relation to children, hence no data is available (Falkov, 1998; Gillam *et al.*, 2003). In addition, there are large differences in the populations studied due to the co-existence of other important variables, hence caution is needed when generalising (Cleaver *et al.*, 1999). The National Household Surveys of Psychiatric Morbidity in Great Britain (Meltzer *et al.*, 1995; Singleton *et al.*, 2000) highlighted this; the prevalence of neurotic disorders was highest amongst lone parents compared to those in couples, indicating family characteristics play a role in prevalence. Oates (1997) quoted studies indicating 25% of new female psychiatric referrals had a child under five and 26% of adults with a diagnosis of schizophrenia living in the community had a child under 16. Moreover, Oates (1997) reported that in Lambeth 60% of women with a serious, chronic mental health problem had children under 16. Although perhaps inappropriate to draw

conclusions about prevalence beyond the specific parameters of each population studied, it is generally agreed that up to 50% of adults accessing adult mental health services will have children at home (Poole, 1996; Falkov, 1998). Young carer literature provides further information about the number of children growing up with parental mental health problems. In a UK young carers' survey 29% indicated they were caring for family members with mental health problems (Dearden & Becker, 2004), suggesting there are approximately 17,000 young carers looking after a parent with mental health problems, based on the 2001 census (Aldridge & Becker, 2003). Considering young carers represent only a fraction of young people growing up in the UK with parents experiencing mental health problems, it is clear parental mental health problems are part of everyday life for a large number of young people.

UK Context

In the UK there are few dedicated services considering the whole family when there are parental mental health problems; with services often failing to recognise when children are present or consider their needs (Howard, 2000). This has led to these children often being referred to as 'hidden and invisible' (Riebschleger, 2004; Elliot, 1992). Whilst some theorise child adaptation in the context of parental mental health problems (Hindle, 1998), stigma and parental fears of child removal play a role in this (Handley *et al.*, 2001), organisational factors also seem important. In particular, the individual orientated approach of adult services seems partly responsible, as they do not routinely consider the family involved. Similarly child services are not designed to focus on adult mental health, so the overlap between adult mental health, parenting and child development is generally not addressed (Falkov, 1998). Aldridge and Becker's (2003) research confirmed that boundaries between adult mental health and children's services are rarely crossed and professionals from mental health teams tend to adopt narrow patient orientated perspectives. This division between services may result in an emotional pressure to take sides, such that sight of the whole family is lost (Hindle, 1998).

The tendency for children of parents with mental health problems to be overlooked is demonstrated by the needs and wishes they express (Bilsborough, 2004; Cooklin, 2006). Young people involved in Barnardos Action with Young Carers identified some key messages for professionals helping their parents (Bilsborough, 2004). These

included wanting to be spoken to, not ignored, given as much information as possible and kept informed. They wanted to be asked what they knew about their parents as they lived with them, be told it was not their fault and who they could contact. Similar needs and wishes were expressed by young people attending Kidstime workshops, as reported by Cooklin (2006). They wanted frank discussions about their parents' mental health problems, an advocate, to know their situation was not uncommon and meet others with similar experiences. They also wanted the opportunity to increase their understanding about mental health problems and whether they would develop them. Help to recognise unacceptable adult behaviour and when their parents were becoming 'ill' important to them, as was identifying and challenging their responsibility beliefs. Further wishes included being listened to when planning their parent's care, recognition and respect for their contribution and knowing how to access help. Moreover, they wanted their daily lives re-established, for professionals to work together, and the positive benefits of their situation recognised. Hence, not only do children want to be more included by services; they need the positive aspects of their situation acknowledged.

Clinicians working with families with parental mental health problems have also advocated the inclusion of children in therapeutic approaches (Fredman & Fuggle, 2000; Daniel & Wren, 2005; Cooklin, 2006). Their active participation in the family construction of practical and adaptive coherent narratives about their parent's mental health is seen as vital (Fredman & Fuggle, 2000; Daniel & Wren, 2005). It is theorised that children witnessing their parents doing unusual things construct stories as a way of generating a coherent explanation (Fredman & Fuggle, 2000). With no explanation of their parents' problems children are vulnerable to generating narratives of personal blame and responsibility, such that a child who is called 'a pest' at times and sent to stay with a friend when their mother is 'tired' and 'sick', may construct a narrative that their mother is 'sick and tired' of them because they are 'a pest' (Fredman, & Fuggle, 2000). This clearly demonstrates the need for a family approach to services.

Crossing Bridges

Almost ten years ago Falkov (1998) edited 'Crossing Bridges', a training resource published by the Department of Health for professionals working with parents with

mental health problems and their children. Based on an integrated ecological model for practice in which mental health problems were set within a social, family, and child development context, the main aim was to improve inter-agency working and support families as a whole. Included was an overview on the impact on children and parents, but also the clear message that not all children inevitably experience difficulties (Falkov, 1998). Integrated services, joint working and prevention were outlined as aims to work towards, yet almost a decade later the lack of a systemic approach in services continues (Aldridge 2006; Stallard *et al.*, 2004). With no centrally coordinated implementation and evaluation strategy, there was a large variation in how much 'Crossing Bridges' influenced practice, as national policy failed to provide a compelling and coherent emphasis on families' needs (Falkov, 2004). Moreover, whilst the training resource is well-researched and informative, it is criticised for lacking attention to basic social and political processes contributing to mental distress (Tanner, 2000). Speaking from personal experience, Tanner (2000) argues her distress about her mother's mental health problem resulted not from her mother's behaviour, but from the associated socially constructed shame and stigma. Thus, it would appear 'Crossing Bridges' went some way towards raising awareness of the family unit, but with little shift in clinical practice and a lack of attention to the wider social and political context.

Encouragingly, with the launch of the parental mental health and child welfare network in 2004, the Social Care Institute of Excellence commissioned several reviews so national practice guidelines could be developed with the National Institute of Clinical Excellence about parental mental health problems. The recent publication of 'Parents in hospitals' (Scott *et al.*, 2007) emphasises the promotion of family contact in adult mental health services. Moreover recognition of parental mental health in national policy documents is growing (see Every Child Matters (DfES, 2003), Social Exclusion Unit Report (Action 16 group, 2004) and Women's Mental Health Strategy (DoH, 2002)). Every Child Matters (DfES, 2003) explicitly highlights children's needs as paramount, with professionals legally bound to prioritise them in families, even when not directly working with them. It is clear that further work in this area is needed, however progress has begun.

Research into children of parents with mental health problems

Risk orientation

One overwhelming characteristic of research into children of parents with mental health problems is the saturation of risk focused research. Since Rutter and Quinton's (1984) seminal research it has been widely acknowledged that these children are at increased risk of developing psychological problems. Their four year study on children of psychiatric patients indicated that one third experience persistent problems, one third transient problems and the rest no problems. The control group showed comparable rates of transient problems but half the frequency of persistent problems. Similar associations have repeatedly been found suggesting children grow up to be users of adult mental health and welfare services and are likely to perpetuate the cycle of dysfunction and disadvantage when they become parents themselves (Devlin & O'Brien, 1999). By the age of 20 a child with an affectively ill parent has a 40% chance of experiencing an episode of major depression and is more likely to have general functioning difficulties, increased guilt, interpersonal and attachment difficulties (Beardslee *et al.*, 1998). A survey by the Office of National Statistics estimated that children with parents who screened positive on a mental health screening questionnaire were three times more likely to have psychological problems than children whose parents did not (Meltzer *et al.*, 2000). Whilst the mental health of children with parents with mental health difficulties has often been the focus of research, it is acknowledged that the risks are all pervasive, with school, social lives, personal and emotional well-being all potentially affected (Aldridge & Becker, 2003).

The risk of harm to children of parents with mental health problems is also frequently highlighted in the literature; this emphasis is understandable given the high profile of child death or abuse cases when parental mental health problems are present and the strong media linkage between mental health problems and violence (Philo *et al.*, 1996). Child protection literature suggests there is a link between child welfare concerns and parental mental health problems, with these present in one third of cases of fatal child abuse (Falkov, 1996) and one quarter of child protection conferences (Farmer & Owen, 1995). Yet, part of the association can be explained by

professionals being more likely to refer these children to services (Aldridge & Becker, 2003; Falkov, 1998). In isolation parental mental health problems present little risk of significant harm to children (Cleaver *et al.*, 1999) and the majority of parents with mental health problems do not abuse or maltreat their children (Falkov, 1998). The interagency guide to safeguarding children (DH, HO & DFEE, 1999) also states that parental mental health problems do not necessarily have an adverse impact on children; hence an individual case basis is advocated when considering risk of harm to them.

Mediators of risk

Although there are numerous studies about parent mental health problems in relation to child outcome, parenting variables are rarely considered or researched (Berg-Nielsen *et al.*, 2002). Whilst mental health problems are linked to children being at increased risk of developing difficulties, there are multifactorial mechanisms of transmission (Garley *et al.*, 1997). Thus, the principles of equifinality and multifinality are important to remember (Cicchetti & Rogosch, 1996). There are multiple pathways to developing mental health problems, not everyone with a parent with mental health difficulties develops problems and not everyone with a problem has a parent with mental health difficulties. When considering the impact on children there is no diagnosis specific effect, thus parental behaviour is a more useful focus, as the associated social and interactional consequences seem more pertinent (Duncan & Reder, 2000). Good quality parent-child relationships require parental warmth and responsiveness, child autonomy, parent-child cooperation and joint parent-child activity; difficulties are thought to arise when these are compromised (Falkov, 1998). Hence it is proposed that children can be affected in the following ways; by the direct effects of parent symptoms, the effect on a parent's capacity to relate to and parent their child, associated alterations in family structure or functioning and associated risk factors (Falkov, 1998).

Children may be directly affected by witnessing self-harm or becoming involved in parental delusions, this may be frightening and confusing; they may come to share their parent's ideas finding it difficult to distinguish between reality and distortions (Duncan & Reder, 2000). Parental withdrawal and self-preoccupation may reduce a parent's availability to their child, perhaps leading to child anxiety, depression,

neglect, exposure to danger and uncontrolled behaviour (Falkov, 1998; Duncan & Reder, 2000). Threats of abandonment, being told 'you'll be the death of me' might be emotionally damaging (Duncan & Reder, 2000). Moreover, unpredictable behaviour, chaotic planning and an inability to anticipate child needs can interfere with the attachment process (Duncan & Reder, 2000); which, combined with a lack of energy, may affect practical caring tasks (Falkov, 1998; Duncan & Reder, 2000). If mental health problems blunt parent emotions or cause them to behave in bizarre or hostile ways, such as being unresponsive, angry or critical towards their children, attachments are likely to be insecure (Cleaver *et al.*, 1999). Children are thought particularly vulnerable if parents experience long term incapacity, loss of parenting function or lack reflexivity about their child's needs, as the risk of neglect and negative experiences increases (Aldridge & Becker, 2003). Separations due to parent hospitalisation, alterations in family roles or marital discord as a result of parental mental health problems may lead to changes in family structure (Falkov, 1998), potentially causing children anxiety.

Isolation, exclusion and social determinants are all important factors in whether parental mental health problems have a damaging effect on children (Aldridge & Becker, 2003). Moreover, the direct effects of parental mental health problems are less influential than the associated social adversity, such as aggression, marital discord, unemployment and poverty (Hall, 2004). This was demonstrated in Rutter and Quinton's (1984) research where the problem mediators were not the mental health difficulties, but the associated psychosocial issues, in particular marital discord. The research showed that exposure to parental hostility and aggression was more important for children than affective symptoms or psychotic manifestations. This is supported by research indicating that levels of parenting social functioning and responsiveness maybe more important for parenting skills than mental health problems, with parental negativity and ineffective discipline the two main dimensions of parenting dysfunction (Berg-Nielsen *et al.*, 2002). Parental negativity is often characteristic of depression, anxiety, eating disorders and some personality disorders, whilst ineffective discipline is most commonly associated with personality disorders and substance-abuse (Berg-Nielsen *et al.*, 2002). In a UK general population study investigating the mediating factors between parent and child mental health problems, negative parent attitudes, involving physical and non-physical punishment were

associated with both parental and child mental health problems and mediated by other family and socioeconomic factors (Vostanis *et al.*, 2006). In contrast, parenting styles combining the use of rewards and lack of punishment were strongly associated with the absence of child mental health problems (Vostanis *et al.*, 2006).

Resilience

Given the dominant parental mental health discourse is one of risk and negativity, it is important to remain mindful whenever there are dominant discourses there are also subjugated discourses representing alternative aspects of experience (White & Epston, 1990). Many children show no indication of adverse outcome when their parents have mental health problems (Seifer, 2003). Resilience models emphasise the positive aspects of individual development, with resilience processes traditionally deemed as any characteristic resulting in a positive child outcome in the presence of risk (Luthar *et al.*, 2000). Yet reviews indicate a paucity of studies examining this in relation to children at risk due to parental mental health problems (Seifer, 2003; Hammen, 2003). Tentative conclusions drawn predominately from inferences of risk focused research suggest more positive parent child interactions, less marital discord, intact families and less family stress result in better child outcomes (Tiet *et al.*, 2001; Hammen, 2003). The relational nature of resilience is further emphasised from an objects relations perspective, with case examples demonstrating the expression and elaboration of affect in families with parental mental health problems seemingly solidifying family relationships and encouraging resilience (Focht-Birkerts & Beardslee, 2000).

Positive factors associated with parental mental health are also strikingly neglected. One key study by Aldridge and Becker (2003) has begun to highlight some of these factors, finding parents with mental health problems can have strong and effective relationships with their children that endure even when other difficulties persist. Moreover, the role adaptations these children make sometimes cement a parent child relationship rather than adversely affecting it (Aldridge & Becker, 2003). Aldridge and Becker's (2003) research indicated parents often put parameters around the caring they allow their children to do, and try to compensate for 'bad' times when their mental health problems improve. Hence, when there are parental mental health

problems, the nature of parent child relationships as reciprocal and equanimous needs recognition.

Quantitative focus, qualitative need

With the majority of research quantitative and focused on child outcome (Mordoch & Hall, 2002; Leverton, 2003), few studies have actively sought the views and experiences of children. Limitations in quantitative methodology are recognised as simplifying phenomena, lacking richness and complexity and preventing the exploration of experience (Barker *et al.*, 2002). Researchers have begun to address these shortfalls by employing qualitative methods; there is now a small, but growing, body of research into this area internationally. As contextual influences differ across countries it cannot be assumed that international studies are representative of the experiences of children in the UK, however they are useful as many have been conducted in similar westernised countries.

Focus group studies involving children aged six to twenty in Canada and Australia (Garley *et al.*, 1997; Fudge & Mason 2004; Maybery *et al.*, 2005) indicate similar themes to those documented by Bilsborough (2004) and Cooklin (2006). These include a quest for understanding about their parents' mental health problems, feeling reassured when their parent's problems are recognised and contextualised, the impact of parent hospitalisation, and the burden of taking on extra roles. All three studies highlighted the importance of family relationships and friendships when coping with parent difficulties and involvement in activities to channel their energy. Strengthening existing support was more important to them than encouraging reliance on external support (Maybery *et al.*, 2005) and they saw strengths in their situations such as their loving rewarding parent and sibling relationships (Fudge & Mason, 2004). Family friendly facilities, access to a broad range of help, including transport and domestic, support groups and mental health problem information were identified by the children as things that might help (Fudge & Mason, 2004; Maybery *et al.*, 2005). However, conflicting views about family meetings and whether to talk to someone were evident (Garley *et al.*, 1997; Fudge & Mason, 2004), indicating an individual basis should be used when deciding how to respond. Interviews with four Australian children, aged eleven to fifteen, of parents with depression echoed these findings. Key themes were struggling to understand parent mental health problems, difficulty coping when not

informed, managing parent's difficulties and the painful impact of parent hospitalisation (Handley *et al.*, 2001). Whilst some of these studies focused exclusively on children of parents with mood disorders (Garley *et al.*, 1997; Handley *et al.*, 2001), the similarity of themes indicated some commonalities amongst young people's experiences.

Meadus and Johnson (2000) phenomenological analysis of three 17 year old Canadian girls' experiences of living with a parent's mood disorder indicated parent unavailability, lack of knowledge and understanding of parent difficulties and adjusting to them were emergent themes. A small sample and sole inclusion of daughters of parents with a mood disorder, led to the suggestion of further studies expanding these factors (Meadus & Johnson, 2000). Similarly, using grounded theory, Riebschleger (2004) looked at the views of five to 17 year olds' living with a parent with mental health problems in America. The focus was on their view of good days and bad days, their knowledge of their parent's problems and their perception of psychiatric services. Results suggested knowledge of their parent's problems was restricted to differences they saw in their behaviour on good and bad days, with good days generally resulting in more attention. They saw other stressors, such as family poverty and divorce, as more powerful than their parent's difficulties and wanted help to be available sooner. All of the 22 involved were participating in a mental health prevention programme and from low income households; hence generalisation of the findings may be limited to this specific context.

A Finnish study using grounded theory to analyse thematic interviews with six children aged nine to eleven and seventeen retrospective narrative accounts again highlighted that children are often not informed about their parent's mental health problems (Polkki *et al.*, 2004). The passivity of parents, consequent constraints on family life and increased responsibility of taking caring roles were emerging themes. Emotions were described as being kept inside, with parental difficulties seen as a shameful secret, children expressed fears and worries about their parent's well-being, alongside considerable loyalty to them. Having good social support, and sometimes family and friends to share experiences, were again described as sources of strength. Yet, with a mixed sample of retrospective accounts and interviews, it was hard to

delineate if there were differences between those recounting and those living the experiences, hence how themes were developmentally relevant was unclear.

The dearth of UK research is noticeable, with only a minority of studies addressing young people's perspectives (Webster, 1992; Armstrong, 2003; Aldridge & Becker, 2003; Stallard *et al.*, 2004). Webster (1992) interviewed twenty children, aged eight to 18, whose mothers were diagnosed with schizophrenia. The key emerging themes of children being a confidant to their parents, having negative attitudes towards their mother's problems and taking on age inappropriate responsibilities were described as negative consequences for children 'split in two'. With no statement of theoretical orientation from Webster (1992), it is difficult to evaluate the impact of researcher bias on the themes; however she concluded attention was needed beyond the negative consequences to focusing on children's compensatory strategies. In Bath, the experiences of children aged six to 17 of parents attending a Community Mental Health Team were explored through semi-structured interviews and compared with their parent's views (Stallard *et al.*, 2004). The interviews focused on the children's understanding of their parent's problems and the effect on their education, care, behaviour and relationships, with frequencies reported of the children's worries and concerns. The limited understanding they had about their parent's problems was highlighted, with half wanting to know more and the majority of children reporting worries about school or their parent's health. Whilst useful in defining the scope of children's concerns, the study did not provide the richness or complexity needed to aid understanding of their experiences.

Young carer research provides the main source of understanding about young people's experiences of parental mental health in the UK. Armstrong (2002) listened to members of a Glaswegian young carers' group, aged 12 to 18, describe how they felt about home life with a parent with mental health problems, and found three main themes; poor understanding of mental health problems, anxiety about their parent's and their own mental health and experiences of economic disadvantage and isolation. Arguing that living with parental mental health problems results in specific needs, often overlooked by generic young carer services, Armstrong (2002) suggested further qualitative research was needed to delineate how support services could help. In a study of 40 young carers, aged ten to 19 in the UK, their parents and key workers, the

inevitability of risk when living with parental mental health problems was challenged (Aldridge & Becker 2003). All the young carers described taking on emotional caring tasks, some experienced stigma, however many did not identify negative consequences, and, rather than consistency of care or parental mental health, they hoped for continuity in their parent relationships. Moreover, the positive consequences of their experiences, such as positive relationships with their parents, increased maturity and better friendships, were emphasised. This study is of key importance opening up an alternative discourse to the risk laden one dominant in the literature, yet it is important to remember caring only represents one aspect of experience, many living with parental mental health problems will not meet the young carer criteria and their experiences remain unheard.

Future research

Employing a positive frame

In general research has continued to focus on the presence or absence of children's psychopathology (Mordoch & Hall, 2002). Much has been from a pathological or problem orientated perspective, with a focus on the negative effects for children. Whilst the association between negative child outcomes and parental mental health problems should be acknowledged, the dominance of this discourse has limited the extent to which alternative narratives are heard. Moreover, the entrenched view of parental mental health problems being problematic for children has meant other influential factors are often overlooked, such as social adversity and marital discord. To redress this balance, further research into the positive factors associated with parental mental health problems and processes associated with resilience would be beneficial (Cogan *et al.*, 2005; Gladstone *et al.*, 2006).

Including fathers

One limitation in parental mental health research is the maternal bias and lack of research on paternal mental health problems (Seifer, 2003; Hammen, 2003; Connell & Goodman, 2002). Fathers have an important role in infant development (Lamb, 1999) yet research has rarely included them. Whilst risk factor studies indicate that partner mental health problems increase the risk of negative child outcomes when there is maternal depression (Hammen, 2003), little attention has been placed on the direct

effects of paternal mental health problems. A recent meta-analysis of 134 study samples showed the presence of mental health problems in mothers and fathers present generally equivalent risks for children (Connell & Goodman, 2002), providing sufficient evidence to challenge the ‘mother blaming’ literature (Phares & Compas, 1992) and highlight the importance of including fathers in future research to overcome this much neglected area.

Young person’s voice

Recent reviews of parental mental health research have underlined the absence of the child’s voice in the literature (Leverson, 2003; Mordoch & Hall, 2002). Research is seen as ignoring the child’s perspective and experiences (Leverson, 2003; Mordoch & Hall, 2002), with attempts to include children ‘extremely scant’ (Gladstone *et al.*, 2006). As traditionally children have only been seen from the viewpoint of various adults and not consulted for their views, conclusions drawn about the consequences of parental mental health problems for children are based on researcher assumptions (Aldridge & Becker, 2003). Gladstone and colleagues (2006) stress how constructions of children will have shaped the research; with the popular view of children, as in need of protection due to physical and psychological vulnerabilities, perhaps biasing researchers’ choice of focus, methods, study populations and interpretations. Advocates of including children in research propose without them the needs and interests of children risk being misperceived (Hill, 1997). Hence one area for future investigation is research focusing on children and young people’s views and experiences.

Experience led research

There is growing recognition of the need for ‘deeper insight’ and qualitative studies about children’s experiences of parental mental health problems (Doran *et al.*, 2003). Mordoch and Hall (2002) in their critical analysis of the literature endorse the use of qualitative methods by arguing they have the advantage of building a more sophisticated understanding of resilience, the impact of stigma and family dynamics and the support young people require. Hinshaw (2004) further advocates the use of qualitative methods in capturing the relevant processes and mechanisms related to the transmission of psychopathology and resilience. He uses his own narrative account about growing up with his father, who had mental health problems, as an example of

the utility of narrative methods and highlights the rarity of family accounts of living with mental health problems. Cogan and colleagues (Cogan *et al.*, 2005) provide further support for this view stating qualitative studies are needed to capture the broader experiential aspects of how children experience difficult family situations. Experiential accounts and qualitative methods have the potential to provide the rich contextualised accounts needed to build understanding in this complex area.

Conclusion

Despite over 50 years of research into parental mental health little is known aside from children being at increased risk of developing psychological problems and negative social, emotional, cognitive and behavioural outcomes. The research has predominately been quantitative with a risk orientated focus, with scant attention paid to positive aspects or resilience processes. Moreover, few have focused on the experiences of families and children's voices are noticeably absent. Whilst parental mental health problems are often referred to, research has been maternally biased. To build knowledge in these areas qualitative methods offer an important alternative, allowing for the richness and complexity of people's experiences to be understood, with the potential to shed light on the complex interactions shaping children's experiences of parental mental health problems. Researchers looking to advance knowledge and understanding in this field need to be explicit about the impact of the social constructions shaping their research and consider the family as a whole, paying close attention to the voices that so far remain relatively absent within the literature and correspondingly in services.

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Appendix 1

Search Strategy Procedure

The search process began with an initial interest in parental mental health based on previous experience of working with families with parental mental health problems. Background information and ideas were sought from textbooks and a provisional list of key themes/ authors in the area of parental mental health was constructed. Government documents were also reviewed to gain information on current guidelines and recommendations for working with children of parents with mental health problems. Ideas about the topic were discussed with supervisors and colleagues.

The topic then became more focused. In conjunction with the Social Care Institute of Excellence (SCIE) systematic map of literature in the area (see below) a detailed search of electronic databases was carried out (see below) to identify the most relevant sources, which were then obtained and read. In addition citation searching, searching the references of obtained articles, web searches and contacting experts in the field were used to gain an up to date understanding of literature in the area and identify any gaps in the current knowledge base.

Social Care Institute of Excellence (SCIE) Systematic Map of Literature

The SCIE produced a systematic map of literature on parental mental health in 2006 to aid research in the area. This was the main source from which relevant literature was identified. The SCIE used a comprehensive search strategy procedure as detailed below and identified 754 studies:

- A wide variety of databases and journals were identified to be searched covering medical, social science, social care and general databases due to the interdisciplinary nature of the topic. The databases searched were as follows: PsycInfo, Medline, EMBASE, CINAHL, HMIC, Cochrane Library, National Research Register, Social Services Abstracts, ASSIA, National Criminal Justice Reference Service abstracts, ERIC, Campbell Collaboration, Social Work Abstracts, CareData, ChildData, Communitywise, SIGLE, Journal searching.
- All searches of databases used a sensitive, detailed search strategy involving the facets:
[parents] [general mental health problems] [substance misuse] [mental health problems specific to parents] [extent] [impact] [interventions] and the Boolean parameters of AND, OR, NOT.
- All databases were searched from 1985 to 2005. Due to the different structures and organisation of each database a slightly different method of searching each database was applied in order to achieve a consistent search strategy.
- In addition to searching databases, journal table of contents were searched for the following journals: *Child Abuse and Neglect*, *Child Abuse Review*, *Children and Society*, *Psychiatric Bulletin*, *Families in Society*, *British Journal of Social Work*, *Health and Social Care in the Community*, *Journal of Substance Misuse*, and *Child and Family Social Work*.

- Key texts on the topic of PMH and interventions were used to identify search terms for the map. In addition, references were gathered from the citation lists of the key texts retrieved.
- The titles and abstracts of all search results were screened against the pre-set inclusion and exclusion criteria. The references meeting the inclusion criteria were then retrieved in full text.

For further information refer to: <http://www.scie.org.uk/publications/map/map01.pdf>

Search Procedure to Identify Relevant Literature since 2005

Databases searched

The following databases were searched:

Pubmed, PsycINFO, Cinahl (Cumulative Index to Nursing & Allied Health Literature), Cochrane database of systematic reviews, AMED (Allied and Alternative Health Database) and the NHS National Research Register (acts a register of ongoing and completed research funded by, or of interest to, the National Health Service). To access grey literature SIGLE (System for Information on Grey Literature) was searched.

The following editing/ expansion procedures were used:

- a) Boolean operators. The Boolean operators (AND, OR, NOT) help refine searches by telling search engines which keywords you want your results to include and exclude.
- b) The truncation technique. An asterisk is placed at the end of a term to search for all terms that begin with that word; for instance depress* will find all terms that begin with depress e.g. depression, depressive, depressed etc.
- c) MESH terminology. This provides a consistent way to retrieve information that may use different terminology for the same concepts.
- d) The key terms/words/concepts and major descriptors identified by the authors of the most relevant articles, were used as search terms.
- e) Search dates were limited to publications since January 2005, due to the comprehensive systematic literature search conducted by SCIE up to this date.
- f) English language publications were included; publications in other languages were excluded.

Searching was conducted using the following search and MESH terms:

(They have been grouped together in similar categories to make it easier to see the different areas searched).

Parent, father, mother, parental, parenting, parent child relations, parenting capacity, families

Mental health problems, mental illness, mental disorder, psychopathology, psychiatric disorders, psychiatric illness

Adolescents, children, young people, young carers

Impact, experiences, understanding

Resilience, coping, risk

Qualitative, interviews, semi-structured, experiences, interpretative phenomenological analysis

Quantitative, questionnaires, surveys

Additional searching techniques

Citation searches

PsycINFO and the Web of Science ISI Citation Indexes (Science Citation Index and the Social Science Citation Index) were searched. These enable cited references to be found (e.g. seminal papers) as well as the authors, articles or journals that have cited these references.

Reference searches

The references of all identified articles were searched for further relevant citations which were subsequently obtained.

Web searches

Web searches were conducted using the search engine 'Google'. The Internet was particularly helpful in accessing government documents, such as 'Every Child Matters' and finding information about current policy developments from the Parental Mental Health and Child Welfare Network.

Contacting 'experts'/ researchers in the field:

Contact was made with researchers currently undertaking research in the area to seek advice and discuss relevant research. Contact was also made with professionals with expertise in the field for the same purpose.

**An Interpretative Phenomenological Analysis of
Young People's Experiences of Living with a Parent
with Mental Health Difficulties**

Cassie Bromley

Submitted in partial fulfilment of the requirements of the University of
Hertfordshire for the degree of DClInPsy

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ABSTRACT

Aims: Recent reviews of parental mental health research have highlighted the absence of qualitative studies exploring the experiences of young people whose parents have mental health difficulties. Given the quantitative risk orientated nature of the majority of the research, concerns have been raised that young people's experiences may be neglected or misunderstood. To address this gap, this study attempted to gain a rich understanding of young people's experiences of parental mental health problems, with the hope of informing clinical practice and improving support for families.

Method: A qualitative approach was chosen, and seven young people, aged 13-15, were interviewed using semi-structured interviews. Interpretative Phenomenological Analysis was employed to analyse the transcripts, with each interview analysed individually before cross case analysis.

Results: The four themes emerging were *Trying to make sense in uncertainty; Talking: good in theory, hard in practice; Reciprocity and connection v frustration and disconnection; and Positive resources and adaptive coping*. The findings highlighted how young people encounter uncertainty when they seek to understand their parent's difficulties and have mixed views on talking about them, informed by family, social and cultural experiences. Their relationships with their parents appeared complex, with simultaneous experiences of feeling cared for and isolated integrated with a desire to look after their parents and, sometimes, frustration at their parent's difficulties. These experiences seemed to foster strong bonds between parents and young people, with some emotional mirroring apparent. Consistent support and adaptive coping were identified as important resources in the young people's experience, with the results suggesting that positive learning can arise from parental mental health difficulties.

Implications: Amongst the many implications identified was the need to support young people around the complex task of making sense of parental difficulties. Families can have a central role in this, and professionals should be aware that developing trusting relationships with young people may be necessary to enable them to talk. Approaching the complex nature of relationships between parents and young people from a positive stance is indicated to be advantageous, as is focusing on their strengths and resources alongside considering issues of risk. Encouraging consistent sources of support for young people through family, friends and the community is also important.

INTRODUCTION

Overview

The experiences of adolescents whose parents have mental health problems have received little attention from researchers. With a dearth of knowledge in this area, professionals and services are likely to make assumptions about their needs on the basis of personal biases, social constructions and the risk dominated research. Without understanding the complexity of adolescents' experiences, services are at risk of not supporting a commonly construed 'vulnerable' population. The NHS drive to place service user perspectives at the forefront (DoH, 2000) gives further weight to the need to increase understanding about adolescents' experiences of parental mental health problems.

My interest in this area stems from my experience of working with families in both adult and child and adolescent mental health settings where parental mental health problems are often present. Experience has taught me that services are seldom structured to focus on families, with adult services mainly individually orientated and child services not designed to focus on adult mental health (Falkov, 1998). The publication of *'Crossing Bridges'* (Falkov, 1998) drew attention to this gap emphasising the importance of interagency working. Moreover professionals (see Bilsborough, 2004; Cooklin, 2006) and the Parental Mental Health and Child Welfare Network continue to advocate for the needs of these children, who are often disempowered by services. Hence research in this area seems invaluable, offering a further opportunity to amplify their neglected voices.

With this in mind, I plan to summarise the narratives currently existing in research about young people whose parents have mental health problems and consider the benefits of discovering alternative narratives and how a qualitative approach lends itself to exploring their experiences. For a more complete review of this area see Bromley (2007). Theories of adolescence will be discussed in relation to how the developmental stage may influence the narratives heard and what specific challenges adolescents of parents with mental health problems may face. Finally, the difficulties in doing research with this population and the research aims will be outlined.

A narrative framework

It is suggested that people organize their experiences in the form of stories (Bruner, 1990); with no single story adequately capturing the broad range of a person's experience. This means that much of a person's lived experience goes unstoried, is obscured, and phenomenologically does not exist because narratives organise a person's field of experience, promoting selective attention to particular events and experiences and inattention to others (Madsen, 2007). The selective focusing of attention is organised by dominant discourses; the global unitary knowledges that serve what is considered appropriate in the cultural and socio-political context (White & Epston, 1990). This means that alternative discourses are subjugated, preventing a multi-verse understanding of experience (White & Epston, 1990). Employing a narrative framework allows attention to be drawn to both dominant and subjugated discourses; this is advantageous when considering parental mental health research as it opens up new possibilities and areas of understanding.

Narratives about children of parents with mental health problems

Over fifty years of research into parental mental health problems has provided little insight into the experiences of their children beyond highlighting the increased risk of developing their own difficulties in a number of areas (Bromley, 2007). With estimates varying due to the lack of attention afforded to these children, it is commonly assumed up to 50% of adults accessing mental health services have children living at home (Falkov, 1998), hence the potential numbers at risk are considered to be high. The risk narrative has grown in dominance since Rutter and Quinton's seminal research (1984) indicating a third of children whose parents have mental health problems develop persistent psychological problems, compared to one sixth of controls. The risk of harm has also been highlighted in child protection literature, with child welfare concerns linked to parental mental health in a quarter of child protection conferences (Farmer & Owen, 1995). The negative effects of parental mental health are suggested to be mediated in various ways, including the direct effects of parent symptoms, the effect on a parent's capacity to relate to and parent their child, associated alterations in family structure or functioning and correlated risk factors (Falkov, 1998). Alongside this risk dominated research is the less apparent message that social factors such as aggression, marital discord, unemployment and poverty have a greater influence on

the risk to these children (Hall, 2004) and that many do not develop difficulties (Falkov, 1998). This highlights the danger of dominant narratives, which become problematic when they constrain us from noticing experiences that might be quite useful (Madsen, 2007). Madsen's (2007) comparison of dominant narratives to double-edged swords helps demonstrate that, whilst they make our world coherent and understandable, they "prune from experience, those events that do not fit with the dominant evolving stories" (White & Epston, 1990, p.11).

Alternative narratives: Shifting to a focus on competence

With mental health services organised around problems and disorders, conversations in services tend to be problem-saturated, with scant attention paid to families' strengths (Carr, 2006). Experiences demonstrating positive aspects often go unstoried and valuable resources unnoticed (White & Epston, 1990). In parental mental health research, risk focused research dominates and only one study highlights the positive aspects of parental mental health problems for children (Aldridge & Becker, 2003). Aldridge and Becker's (2003) research demonstrates that parents with mental health problems can have strong and effective relationships with their children, enduring even when other difficulties persist. Moreover, they highlighted that the role adaptations children make sometimes cement parent-child relationships rather than adversely affect them, that parents often put parameters around their children's caring and try to compensate for 'bad' times when their mental health improves. A positive approach increases learning about how to prevent difficulties occurring and how to build qualities that help families not just survive, but also flourish (Seligman, 2005). Taking such an approach does not prevent consideration of risk issues or child protection, nor does it minimise the negative experiences of some children; instead it widens the scope of what is heard and broadens understanding. Hence, redressing the research balance with a focus on the positive factors associated with parental mental health problems and processes associated with resilience is encouraged (Cogan, Riddell & Mayes, 2005; Gladstone, Boydell & McKeever, 2006).

Employing a qualitative approach to re-search young people's experiences for alternative narratives

Historically research in parental mental health has mainly been quantitative and therefore unable to provide information about the richness and complexity of young people's experience, hence qualitative approaches are advocated by some researchers (Mordoch & Hall, 2002; Leverton, 2003). Moreover, many have highlighted the lack of inclusion of young people in parental mental health research (Gladstone *et al.*, 2006, Leverton, 2003; Mordoch & Hall, 2002). Encouragingly, some international research has begun to address this, with qualitative studies involving young people now emerging (Fudge & Mason, 2004; Garley, Gallop, Johnston & Pipitone, 1997; Handley *et al.*, 2001; Maybery, Ling, Szakacs & Reupert, 2005; Meadus & Johnson, 2000; Polkki, Ervast & Huupponen, 2004; Riebschleger, 2004). In the UK a handful of studies, drawing predominantly on young carer samples, have been published (Aldridge & Becker, 2003; Armstrong, 2003; Stallard *et al.*, 2004; Webster, 1992). A review of all these studies is presented by Bromley (2007). Common themes arising from these include young people's lack of understanding about their parent's problems, anxiety about their parent's and their own mental health and experiences of economic disadvantage and isolation. With the exception of Aldridge and Becker's research (2003), none have focused on the positive aspects of young people's experiences; hence this remains a research gap. The benefit of using qualitative approaches to explore young people's perspectives is the potential to gain real insight into their experiences as their accounts have greater validity than third person accounts offered by researchers and professionals.

Adolescence

Theories of adolescence

This section only gives a brief overview to some of the main ideas relevant to this research, for a comprehensive understanding see Miller (2002). Adolescence is typically viewed as the transition between childhood and adulthood, a time of physical, cognitive and emotional changes (Coleman & Hendry, 1999). Psychosocial models suggest the main issues facing adolescents are the development of independence, sexual identity, self-identity and self-control of aggression (Lancaster, 1999). Newman and Newman's (2003) revision of

Erikson's psychosocial developmental model conceptualises the main process of early adolescence as gaining a group identity versus peer alienation, with peer group affiliation satisfying the need to belong in a context outside the family. The main process of late adolescence is seen as identity formation versus role confusion. If adolescents are able to integrate various identifications into a more complete identity, they are prevented from having a fragmented personality lacking a core, known as 'identity diffusion' (Erikson, 1965). Factors seen as relevant to negotiation of these tasks are previous childhood experiences, parent-child relationships and the capacity to cope with the stresses of adolescence (Lancaster, 1999). Although stage theories are limited, because they are based on culturally specific norms and generalisations, they indicate the potential developmental processes specific age groups may face.

Piaget's cognitive stage theory (Piaget, 1971) suggests that adolescents move into formal operational thinking as the last stage of cognitive development. This is conceptualised as logical, abstract and flexible thinking, allowing people to reflect, apply mental operations to propositions and consider abstract ideas about the possible, real, future and present. Although this theory has received criticism because of the inadequate support for stages, inadequate accounts of the development mechanisms, underestimation of abilities and slighting of emotional and social development, it offers an insight into the complexity and richness of cognitive development (Miller, 2002). Based on this theory, adolescents may have the ability to reflect on their experiences, possibly leading them to a different understanding to one they had when younger.

How adolescence may influence the narratives heard

Given the developmental processes considered key to adolescence, it is possible that narratives of adolescent experiences may focus around the impact of independence and separation and how these are negotiated in the context of parental mental health problems. However, there is huge variation in individual development and normative models can only give an indication about the possible processes relevant. What is certain is that each adolescent's context will play a role in the narratives heard, as people are profoundly shaped by their social context (Madsen, 2007). It is equally important to be mindful of how researcher perceptions will influence the narratives adolescents share. As Tomm (1992) indicates perception is not a passive process of observation but an active drawing of

distinctions, hence researchers elicit and evoke certain narratives whilst inhibiting others. Thus, whilst developmental processes may or may not influence the narratives heard, the context and researcher will undoubtedly have an impact.

Specific challenges for adolescents whose parents have mental health problems

It is generally assumed that mental health problems may compromise a parent's capacity to offer a secure attachment relationship, adequate stimulation and authoritative parenting (Carr, 2006). Moreover they may predispose children to developing psychological difficulties through modelling, inadvertent shaping and reinforcement, whereby children learn belief systems, behavioural patterns and coping strategies similar to their parents (Carr, 2006). However, in addition to these general processes, the developmental processes associated with adolescence have been suggested to present specific challenges (Lancaster, 1999). These can be understood in terms of the effects seen on health, school life, identity, family and social relationships, and emotional and behavioural development.

Health effects can include having to cope alone with puberty due to parents being unaware of their child's worries, or adolescents having sexual relationship problems due to lack of effective guidance (Cleaver, Unell & Aldgate, 1999). In terms of school, academic achievements may be compromised if adolescents feel overwhelmed by their parent's problems (Lancaster, 1999). They may miss school to look after their parents or siblings and their parents may not be able to offer the encouragement needed to help them achieve (Lancaster, 1999). If a parent's problems take precedence, low self-esteem may arise and adolescents may not feel secure enough to develop their own identity (Cleaver *et al.*, 1999; Lancaster, 1999). Separating from parents and developing interests outside the family may also be difficult because of parent dependency needs (Meadus & Johnson 2000). Adolescents may be cautious of exposing family life to outside scrutiny, restricting their friendships (Cleaver *et al.*, 1999). Feeling painfully different to their peers they may avoid social contact or seek out a 'fringe' peer group due to feelings of shame and embarrassment (Lancaster, 1999). Similarly, expanding social networks may be hindered if additional family responsibilities have been assumed (Lancaster, 1999). Fears of family break up and feelings of isolation can arise (Cleaver *et al.*, 1999). Moreover identification with their parent may lead to symptoms being replicated by adolescents or overt rejection of their parent, with feelings of guilt emerging (Lancaster, 1999). With increased cognitive capacity

the full implications of parental mental health problems may become apparent, possibly leading to denial, attempts to hide the reality from the social world and self, or distress (Lancaster, 1999). Adolescents may have difficulty developing constructive coping strategies if they have seen their parent cope by using maladaptive strategies, such as suicide attempts. Self-blame and guilt about their parent's difficulties may occur, with problems arising if adolescents deny their own feelings and needs (Cleaver *et al.*, 1999).

What is striking about the consequences highlighted here is the singular negative perspective. This reflects the body of research and tendency to take a problem-orientated approach. As Bandura argues there has been an inclination to be "more heavily invested in intricate theories of failure than in theories of success" (Bandura, 1998, p. 3). Being mindful of the socially constructed nature of research and what is considered worthy of attention, it seems timely to explicitly adopt a positive psychology approach and focus on what needs to be understood about human behaviour to enhance people's quality of life (Maddux, Snyder & Lopez, 2004). Once again it demonstrates the need for the research scope to be widened, allowing for positive consequences and outcomes to be explored and heard.

Barriers to entering into research conversations with adolescents

One difficulty encountered when trying to explore young people's experiences of parental mental health problems is they are a relatively 'hidden and invisible' population (Elliot, 1992; Riebschleger, 2004). Services' failure to recognise when children are present or consider their needs is well documented (Howard, 2000). With data rarely collected on whether adults accessing mental health services have children (Falkov, 1998), accessing this population is not straightforward; researchers attempting to do so often comment on the difficulties accessing them (Aldridge & Becker, 2003; Handley *et al.*, 2001; Stallard *et al.*, 2004). Issues of stigma and parental fear of children being taken away may prompt secrecy and self-imposed isolation, resulting in many individuals affected by mental health problems being reluctant to participate in research (Handley *et al.*, 2001). Stallard and colleagues (2004) reflections on why only 57% of their eligible sample participated suggested there were perhaps adult mental health team, parental and child barriers to accessing this population. The adult mental health team barriers identified were time pressures, resource limitations and a traditional client-focused approach, leaving little time for the consideration of child needs. In addition, adult mental health professionals felt they lacked child focused

skills and wanted to protect the needs of their clients by not placing them under scrutiny. Parental barriers were hypothesised as parental preoccupation with their own needs, denial that their children may be affected and a wish to protect them from talking about possibly upsetting events. Similarly, children's reluctance was hypothesised as protective; with some perhaps anticipating negative consequences from discussing their parent's difficulties. Aldridge and Becker (2003) also reported difficulties recruiting young carers; suggested reasons included young caring being purposively concealed or obscured without intention and parental reluctance to share the nature of their difficulties and children's caring due to fear of children being taken into care. Research topics perceived as sensitive or threatening present a substantial challenge to recruitment, this area is seen as a prime example of this (Cogan *et al.*, 2005). Given the excessive negative emphasis of the research, it is perhaps unsurprising that many negative effects appear bound up in research participation, with researchers finding it difficult to access this population.

Aims of the research

Research in parental mental health has been constricted by a dominant risk orientated narrative. Through consideration of the benefits of taking a positive psychology approach (Seligman, 2005) and a focus on competence, the need to widen the research scope is evident. With the emphasis to date on quantitative research, little is understood about the richness and complexity of young people's experiences when living with parental mental health problems. Consequently there is growing recognition that qualitative research including young people is required to address this gap in knowledge (Leverson, 2003; Mordoch & Hall, 2002). Thus, the objectives of this study were to explore adolescent experiences of living with parental mental health problems using a qualitative approach. The aim was to offer a rich descriptive and interpretive account, paying attention to the contradictions, complexity and context of adolescent experiences. Particularly interested in exploring the positive aspects to adolescents' experiences, their strengths, resources and competencies, whilst remaining attentive to issues of risk, I wanted to develop an alternative narrative to the negative one that dominates. The hope is, through developing a better understanding of adolescents' experiences, clinicians will be more able to offer helpful and supportive services to families with parental mental health problems and strengthen their existing resources.

Research question

With the above aims in mind the main research question was framed as:

- How do adolescents experience their parent's mental health problems?

METHODOLOGY

This section outlines the rationale behind the chosen method, describes participant recruitment, collection and analysis of data and explains how I endeavoured to meet research quality guidelines.

A qualitative approach

To date qualitative approaches to young people's experiences of parental mental health problems have been relatively neglected (Leverton, 2003; Mordoch & Hall, 2002), resulting in "an impoverished map of psychological knowledge" (Smith, 1996, p. 265). Qualitative approaches can enrich existing research, being ideally suited to explore people's experiences in depth or novel areas (Barker, Pistrang & Elliott, 2002). Such an approach was therefore chosen for this study.

Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) (e.g. Smith, 1996; Smith & Osborn, 2003; 2008) was chosen as the methodology for several reasons.

Firstly, the utility of IPA has been demonstrated in psychological research. Initially gaining momentum in health psychology, there is now a growing body of IPA research in clinical psychology (see Knudson & Coyle, 2002; Rhodes & Jakes, 2000). To date, there are no published UK IPA studies exploring young people's experiences of parental mental health difficulties.

Secondly, IPA is consistent with the research aims; to explore in detail how participants make sense of their world to get an insider perspective (Smith & Osborn, 2003; 2008). The underlying philosophy being there is no objective reality, but rather people's experiences are influenced by their perceptions, which are constrained by social constructions. The researcher tries to make sense of the participant trying to make sense of their world, resulting in a double hermeneutic process (Smith & Osborn, 2003; 2008), giving rise to both the phenomenological and interpretative aspects of the approach. The interpretive account

produced is positioned in relation to the wider social, cultural and theoretical context, providing renewed insight into the phenomenon (Larkin, Watts & Clifton, 2006).

Thirdly, IPA's idiographic nature matches the research objective; to report in detail about the participants rather than making premature general claims for the larger population (Smith & Osborn, 2003; 2008). Analysis aims to highlight generic themes, in addition to each participant's individual story, thus examining both divergence and convergence (Smith, 2004). It is suggested that delving deeper into the particular takes us closer to the universal and the 'essence' of experiences (Smith, 2004).

Finally, IPA's stance in relation to the researcher's role complements my epistemological position. Drawing on the social cognitive paradigm premise, it is hoped that, through understanding cognition, the quality of an individual's experience will be captured (Smith & Osborn, 2003; 2008). It is recognised that access to another person's experience is partial and complex; hence IPA pays close attention to the researcher's role in influencing the process (Smith, 1996; Smith & Osborn, 2003; 2008). Knowledge produced will be dependent on the researcher's standpoint as they cannot escape the influence of their biographies and preconceptions (Smith, 2004). Consequently reflexivity is seen as vital in aiding transparency. It is acknowledged any discoveries made will be a function of the relationship between the researcher and participant, accounts being constructed and shaped by the encounter (Larkin *et al.*, 2006).

Strengths and limitations

One of IPA's fundamental benefits is it returns people's experiences to the forefront (Larkin *et al.*, 2006), fitting with the NHS agenda of taking a 'patient centred perspective', acknowledging service users' voices (Brocki & Wearden, 2006; Reid, Flowers & Larkin, 2005). To a novice qualitative researcher like myself its clear guidelines regarding application are appealing (Smith & Osborn, 2003; 2008). Furthermore, IPA research has the scope to be less deficit focused, fitting with positive psychology (Reid *et al.*, 2005). An undoubted strength of IPA is its inductive nature, allowing unanticipated themes to emerge (Smith, 2004). Ideal for exploring complexity in people's experiences, IPA's openness guards against limiting the focus to existing knowledge (Smith & Osborn, 2003; 2008).

Some of IPA's limitations are consequences of its strengths. IPA has been criticised for lack of clarity about the interpretation level required, with concern that first order analysis, merely summarising but not developing participants' concerns to an interpretative or conceptual level, is seen as sufficient (Larkin *et al.*, 2006). Larkin and colleagues (2006) think this undermines IPA's potential to properly communicate participants' experiences. The lack of guidance on how reflexivity should be incorporated and how researcher conceptions influence analysis have been highlighted as weaknesses, with critics suggesting that findings tend to invoke a sense of discovery rather than construction (Willig, 2001). However, IPA's proponents argue it is an approach rather than a rigid method, so whilst some find the lack of prescription wanting, its advantage is its flexibility to meet the research need and context (Smith & Osborn, 2003; 2008; Smith, 2004).

IPA requires participants to articulate their experiences with a degree of sophistication (Willig, 2001). The reliance on people's ability to successfully communicate is seen as limiting as they may be unable to convey the subtleties of experience with language (Willig, 2001). Smith and Osborn (2008) acknowledge there are many reasons why people struggle to express themselves, arguing the researcher's job is to interpret people's emotional states from what is said and ask critical questions about what is unspoken.

A further limitation is the role of language. Social constructionists argue language constructs rather than describes reality; hence interviews only tell you how someone talks about experience rather than experience itself (Willig, 2001). The extent of this limitation is a matter of degree, as IPA acknowledges the role of social constructionism and the action-orientated nature of language, yet it challenges the narrow view of people only as discursive agents (Eatough & Smith, 2006).

Why not other qualitative methods?

When considering which method would be most appropriate grounded theory, discourse analysis and narrative analysis were ruled out. Grounded theory was judged unsuitable because of its positivist underpinnings, emphasis on theory construction and hence privileging of data convergences (Charmaz, 2008). As one of the main limitations in parental mental health research has been the tendency for a narrow approach at the expense of

hearing alternative voices and divergences between young people's experiences, IPA seemed more suited to explore the richness and complexity of individual experiences.

Discourse analysis was ruled out because of its strong emphasis on language as social action and rejection of cognition's central role (Willig, 2008). I view cognition as important, seeing meanings as constructed by individuals within a social and personal world (Smith & Osborn, 2008). Hence I take a 'both and' stance (Andersen, 1987), a "light social constructionist position" (Eatough & Smith, 2006, p. 485). As such discourse analysis was unable to meet the research aims, as the research question's inherent assumption was that people make sense of experiences independently of, and within, social interactions.

Narrative analysis is often used when investigating experiences involving transitions and identity renegotiation. Concerned with the narratives people construct to bring order and meaning to the constantly changing flux (Murray, 2008), it gives voice to those absent from mainstream discourse (Collie, Bottorff & Long, 2006). Although sharing similarities with IPA, I felt narrative analysis's specific emphasis on temporal narratives might limit the research, whereas IPA's openness would allow for narratives to be heard if relevant. Accordingly I concluded IPA provided the best methodological fit with the research question.

Participants

Recruitment

In light of difficulties reported by researchers when recruiting participants in this area (Aldridge & Becker, 2003; Handley *et al.*, 2001; Stallard *et al.*, 2004), both the NHS and voluntary sector were used to widen the scope.

Initially several voluntary organisations were contacted including Rethink, Mind and Young Carers Projects. Responses were mixed, with many supportive of the research but unable to spare time for involvement. Some were unable to find willing participants, others felt young people would not want to participate. Many reported young people lacked awareness of their parent's difficulties or conceptualised them in different ways so would not view the research as relevant.

In the voluntary sector one of the Family Welfare Association's Parental Mental Health Support Projects and a Young Carers Project assisted with recruitment. Both services were enthusiastic, viewing the research as valuable, which was reflected in their efforts recruiting. For further details about the services see appendix 1.

In the NHS two Child and Adolescent Mental Health Services (CAMHS) assisted in recruitment. The research project was presented to both teams during their weekly meeting; their participation was supported through regular liaison and my supervisor's encouragement.

These services agreed to identify potential participants and explain the research. Those interested in participating completed consent forms and were contacted to arrange interviews. Finding young people willing to participate proved quite difficult. Nine young people were approached by clinicians in CAMHS, three consented to participate. Nine were identified by the Parental Mental Health Support Project co-ordinator, three consented to take part. Four young people were approached by the Young Carers Project, three took part. One of those consenting did not participate due to difficulties arranging an interview; numerous interviews were arranged which the parent reported repeatedly forgetting to attend.

Inclusion and exclusion criteria

To ensure the sample was sufficiently homogenous, participants had to be aged 13 to 18 and living with a parent with a current or recurrent mental health problem. The age range is commonly used in research with adolescents and developmental models use similar age bands (Newman & Newman, 2003). However, because the developmental issues faced by a 13 and 18 year old might be quite different, it was planned participants who were more similar in age (either 13–15yrs or 16–18yrs) would be recruited if there was enough interest. The criteria for defining parental mental health problems was kept broad, including any parent in contact with a health professional for mental health problems, be it their GP or a Community Mental Health Team. Parents with a current mental health diagnosis but not in contact with services also met inclusion criteria. The final criterion was that participants spoke English fluently. Due to resource limitations, the heavy reliance of qualitative research

on language and concern that meaning might get lost in translation, non-English speaking adolescents were excluded.

The sample

Participants were seven adolescents aged 13-15 living with a parent or carer with mental health problems (see table one for details). The sample was ethnically diverse, thus representative of the local population. Six of the seven lived with a single parent or carer, five lived in social housing and two were twins.

Table 1

Participants

Participant pseudonym	Gender	Age	Ethnicity	Living with...	Parental mental health difficulty	Approximate length of difficulty
Alara	Female	13	Turkish	Mother*	Depression	8 years
Anna	Female	15	Indian	Mother* 4 younger siblings	Depression	10+ years
Emir	Male	14	Turkish	Mother* 2 younger siblings	Depression	4 years
Katie	Female	13	Irish American	Mother* Father younger sibling	Depression and anxiety	Since childhood
Hayley	Female twin	13	Black Caribbean	Aunt* Older sibling and cousin	Traumatic bereavement, depression.	6 years
Chris	Male twin	13	Black Caribbean			
Emily	Female	15	Black African	Mother* Grandmother Younger sibling	Anxiety Depression	15+ years.

*indicates parent or carer with mental health problem

In addition to those described, a further participant attended for an interview, which was not carried out. Misunderstanding the research topic, they did not feel it was relevant to them when explained. On checking with the person who recruited them, they clarified the participant was informed of the research topic and met the inclusion criteria.

Context

The services which helped recruit were all based in the inner London borough of Hackney; ethnically diverse, with a population of 207,000 people, more than a quarter of whom are under 19 (Hackney Council, 2006). Ethnic minority groups account for 53% of the young people, the largest of which are black African (30%), white other (11%) and black Caribbean (10%) (Hackney Council, 2006). It is thought likely the ‘white other’ population mainly comprises of Turkish and Jewish young people as they have strong communities in Hackney (Hackney Council, 2006).

Hackney has high levels of poverty and inequality, with almost 38% of the young people affected by deprivation; 46% of under 20’s live in overcrowded households and one third in single parent households (Hackney Council, 2006). The link between poverty, social inequality and mental health has repeatedly been recognised (Murali & Oyebode, 2004), hence it is unsurprising that Hackney has high rates of mental health problems, with rates of ‘schizophrenia’ and ‘neurosis’ among the worst in inner London, and ‘schizophrenia’ rates three times the national average (Hackney Council, 2006). The health deprivation index rates virtually the whole borough within the most deprived 30-40% of areas in England, with the majority in the top 10-20% (Hackney Council, 2006).

Ethical issues

Ethical approval was granted by the University of Hertfordshire for recruiting from voluntary organisations and by Hounslow and Hillingdon NHS Research Ethics Committee for recruitment through the NHS. Relevant documentation is included in appendix 2.

Informed consent

Information sheets and an introductory letter outlining the research purpose, what participation involved, confidentiality, anonymity procedures and the right to withdraw were given to participants and their parents to ensure informed consent (see appendix 3, 4 & 5). This information was also given verbally prior to interviews with the opportunity to ask questions. Participants signed a written consent form, countersigned by the researcher (appendix 6), as did parents of participants under 16 (appendix 7).

Confidentiality

Confidentiality and its limits were explained to all participants and parents. They were made aware that all personal identifying information would be removed, such that only basic descriptive information would be included to situate the sample in line with good qualitative research practice (Elliott, Fischer & Rennie, 1999). They were informed that information would not be shared with parents or services, although it would be shared with appropriate others if someone was thought to be at risk.

Affiliation of the study

An ethical concern was potential participants might assume the service they received would be affected in some way by their decision regarding participation. Thus the information sheets highlighted that the research was independent of the service they received and would not affect it.

Potential distress

Whilst some research participants describe the process of reflecting on their past experiences as therapeutic (Birch & Miller, 2000), an ethical consideration was the potential distress experienced by young people when enquiring about their parent's mental health difficulties. As a trainee clinical psychologist I had experience of dealing with people in distress and I endeavoured to conduct the interviews as sensitively as possible. I made it clear, both verbally prior to interviews and on the information sheets, that participants need not answer any questions they were uncomfortable with and could stop the interview at any time. I also made myself familiar with local services they could access for further support and allocated time at the end of interviews to debrief.

Data collection

Interviews

A semi-structured interview schedule was developed (appendix 8) based on relevant literature (see Bromley, 2007), discussions with my research supervisors and guidance on interview schedule development (Rubin & Rubin, 2005; Smith & Osborn, 2003; 2008). The schedule was used flexibly to facilitate conversation and encourage detailed descriptive accounts. Following each interview the schedule was reviewed to incorporate new areas of interest if appropriate. As I had no previous contact with participants the interview process was guided by the information they chose to share.

Participants were given a choice about the interview location. Four chose to be interviewed at home and three at the Young Carer's Project. The twins chose to be interviewed together. Interviews lasted between 25 and 75 minutes, were audio taped and then transcribed, with all identifying information removed or disguised.

Following each interview I completed a response sheet (appendix 9) aimed at increasing reflexivity and consideration of the interview process and content. I noted initial thoughts and impressions in addition to factors possibly affecting the interview, such as interruptions.

Data analysis

Data was analysed using IPA, as detailed by Smith (Smith, 1996; Smith & Osborn, 2003; 2008). The process was also informed by guidelines for ensuring quality in qualitative research (Elliot *et al.*, 1999; Spencer, Ritchie, Lewis & Dillon, 2003) and through supervision from an experienced IPA researcher.

Individual case analysis

Each transcript was analysed individually in turn. Smith and Osborn (2003; 2008) point out that this helps researchers remain open to new issues emerging and divergences in data, whilst also noticing convergences with previous analysis. Transcripts were read repeatedly and initial annotations made in the first column summarising the content, alongside

commenting on connections, preliminary interpretations and contradictions. Following initial analysis, transcripts were re-read and the second column used to document emerging themes. This required moving from initial ideas to an interpretive level of abstraction, general enough to allow theoretical connections across cases to be made whilst still grounded in the text. The twins' interview was analysed as a complete transcript because separate analysis did not appear to add value, due to consistency between the emerging themes from each twin.

Emergent themes

The emergent themes were listed in order of appearance, connections between them were sought and themes clustered. Smith and Osborn (2003; 2008) describe this process like using a magnet; some themes pull others in, helping to make sense of them. The clusters of themes that emerged were named to capture the essential quality of the text's meaning and formed the super-ordinate themes. The iterative nature of this process involved close interaction with the text with continual checking of interpretations and themes. Key sentences from the verbatim text were chosen to represent each theme; ensuring they were grounded in the text. Next a table of emergent themes was produced, including the super-ordinate and sub-themes with corresponding text extracts. For an example of the entire analytic process of one interview see appendix 10.

Cross case analysis

After all the interviews had been analysed individually a table of themes was constructed. This was used for cross case analysis, with themes clustered into super-ordinate themes, such that a coherent framework was developed regarding the young people's experiences. Transcripts were reviewed in light of the emerging super-ordinate themes, resulting in a master list of themes.

Writing up

The master list was translated into a narrative account, with the analysis expanded and themes explained and illustrated with verbatim extracts. A clear distinction was made between what young people said and interpretations made.

Quality in qualitative research

Establishing the quality and rigour of qualitative research presents different challenges to quantitative methodology, with its positivist epistemology (Yardley, 2008). Acknowledging this, several authors have offered guidance for evaluating qualitative research (Elliott *et al.*, 1999; Spencer *et al.*, 2003; Yardley, 2008) which directed this study. Spencer and colleagues' (2003) four guiding principles of quality qualitative research are discussed below in terms of the steps taken to meet them.

Research as contributory

Spencer and colleagues (2003) assert that quality qualitative research should be contributory and advance wider knowledge or understanding. The relevance of, and need for, this study was outlined in the introduction and literature review (see Bromley, 2007). The analysis was reviewed in light of the literature and existing knowledge. Particular attention was also given to how the research could contribute to clinical practice.

Defensible in design

A defensible design is defined by Spencer and colleagues (2003) as one that addresses the research questions posed. A thorough explanation of the choice of design in relation to the research aims is presented earlier in this section.

Rigorous in conduct

Systematic and transparent data collection, analysis and interpretation are seen as markers of rigorous conduct in Spencer and colleagues' (2003) guidelines. To ensure transparency, an audit trail has been provided in appendix 10. Furthermore, self-reflexivity sections have been included to aid transparency about my motivation for the research and to locate myself in context. Peer review was utilised to ensure rigor, with two audits of analysis conducted. Both audits were carried out by my supervisors, clinical psychologists specialising in child and

adolescent mental health, one of whom has extensive experience in using IPA. Both agreed with the themes produced, feeling they could be justified from the transcripts. In addition regular discussion with my supervisors and peer IPA researchers throughout analysis about emerging themes, similarities and differences enabled the overall process to be reviewed. It also provided space to consider alternative interpretations and reflect on personal and cultural influences when interpreting the data. Whilst the limitations of peer review are acknowledged, no-one being as involved with the data as the researcher, it does allow for analysis coherence to be checked (Angen, 2000). Moreover, as a novice IPA researcher, peer review felt particularly valuable.

Credible in claim

Spencer and colleagues (2003) propose that well founded and plausible arguments are essential for research to be considered credible in claim. To this end themes have been illustrated with verbatim extracts from interviews; allowing readers to evaluate the fit between the data and my interpretations (Elliott *et al.*, 1999).

Participants were provided with the opportunity to comment on data analysis, as recommended by Smith (1996) and Elliot and colleagues (1999). All were sent a copy of their interview transcript and a summary of the main themes (example in appendix 11). This was to ensure the interpretations made sense to them and, from an ethical position, to ensure they understood how their data was being used. Critics of participant feedback suggest it relies on a positivist assumption there is a fixed truth to which the results can be compared (Angen, 2000). Yet, social constructionist epistemology indicates there are multiple realities and understanding is co-created, hence checking participant views can lead to a richer understanding in which multiple perspectives are welcomed rather than searching for a singular truth (Smith, 1996). One problematic aspect is the power dynamic between researcher and participant, such that participants may feel unable to disagree with the researcher (Smith, 1996). The feedback I received suggested this was not so, as some communicated negative feelings.

Professionals in the field were invited to comment on the coherence and comprehensibility of the analysis and extent to which it resonated with their personal and professional

experiences and existing literature. Triangulation traditionally works from the premise that multiple methods, investigators or data sources will converge meanings about a topic and thereby suffers from criticism as fundamentally positivist (Angen, 2000). However, it can enrich data as viewing a phenomenon from different perspectives can capture multiple 'voices' (Smith, 1996; Yardley, 2008).

Sample characteristics and the study context are outlined, as recommended by Elliott and colleagues (1999) in order for the findings' transferability to be judged.

Self-reflexivity

I am a white British female, aged 26, who grew up in a middle class town outside London and has worked in psychology for five years. A combination of my Clinical Psychology training, experiences working in the NHS and personal values have informed my theoretical position, leading me to favour social constructionist, systemic and narrative ideas both in research and clinical practice. My understanding of mental health problems is informed by a formulation perspective; I view them as an understandable experience to which everyone is vulnerable under certain circumstances. My preference is to reject labelling of difficulties based on invalid categories and poorly evidenced biological explanations; instead I view difficulties as occurring on continuums and influenced by a combination of psychological, social and biological factors. I have become increasingly aware of the impact of social and environmental influences on mental health and the disparities that exist. I consider positive psychology, favouring the strengths and resources of people, particularly helpful for working with individuals and families.

My interest in children whose parents have mental health problems was sparked by their media portrayal in various dramas and my experience of working with families and individuals where these problems were present. I have been struck by the stigma associated with mental health problems and the tendency for an individualistic approach at the expense of a whole family perspective. My view is that children whose parents have mental health problems are often overlooked; their experiences unacknowledged. My interest in families, positive psychology and social constructionism has led me to develop the current study. My hope is to draw attention to the voices of these children and gain a greater understanding of the complexity of their experiences. My beliefs and assumptions have inevitably shaped my

contribution to co-constructing meaning with the study's participants and it is important this is acknowledged. Whilst in line with IPA I privileged an open approach in the interviews to try to enter the psychological and social world of the young people, it is likely my questions and non-verbal communications may have encouraged, or discouraged, particular responses and a different researcher may have elicited different responses.

Interviewing the young people in their homes gave me an appreciation of their context. I was highly aware of the contrast between my background and the poor living circumstances some faced. The desperation of some of their situations was highlighted when one mother asked whether I could talk to the council to help them get better housing; there were six people living in a one bedroom flat in a poor state. I was saddened by their circumstances, powerless to help. Moreover, I was relieved I did not have to endure the conditions they did and felt guilty knowing I could return to a better environment. Most of all I respected their ability to manage in such deprivation, increasing my motivation to represent their experiences effectively.

I feel the impact of researching in a deprived community heightened my reactions to families' difficulties, perhaps silencing me to some extent during interviews. Feeling overwhelmed by some of the young people's situations, I was sensitised to cues about their level of comfort and willingness to talk and perhaps more gentle and less exploratory around areas where I felt they were emotionally vulnerable. My caution was partly influenced by changing from clinician to researcher; I found it difficult to reconcile the difference in my responsibility. Knowing I would not have ongoing contact I wanted to guard against upsetting them. Also, because of recruitment difficulties, I was keen to ensure those who participated had a positive experience. I felt recruitment problems might reflect reluctance talking about the topic and wariness about research. Likewise, this message was relayed to me by the services helping recruitment, with people often highlighting the delicate nature of some of the families' situations and the importance of interviewing with sensitivity and care. A further factor, perhaps increasing my caution, was the long and challenging process of gaining COREC and R&D approval, which sensitised me to potential difficulties, possibly inflating ethical concerns. Through discussions with my supervisors I realised it was important to represent the young people's experiences in the best way possible, their informed consent demonstrating they had knowingly agreed to be questioned in a way that

would uncover this. Moreover, I reminded myself there were safeguards in place if they felt distressed or changed their minds about participation, allowing me to remain curious.

RESULTS

This section presents the results of the Interpretative Phenomenological Analysis of young people's experiences of living with a parent with mental health difficulties. Through analysis, an account was developed of how participants came to understand their parent's difficulties and the impact on their lives and their relationships.

Four key themes, summarised in Table 2, emerged to form the basis of this account. The themes are:

- *Trying to make sense in uncertainty*
- *Talking: good in theory, hard in practice*
- *Reciprocity and connection v frustration and disconnection*
- *Positive resources and adaptive coping*

These themes are one possible account of how young people experience living with parents with mental health difficulties. They do not cover every issue raised or every aspect of their experience, but were selected due to their salience in relation to the research questions. Moreover, this account is partial and subjective, such that other researchers may have highlighted different aspects. The four super-ordinate themes and related subordinate themes are explored and illustrated with verbatim extracts from the interview transcripts¹.

¹ In presenting verbatim extracts, some minor changes have been made. Minor hesitations, a repeated word or words such as "erm", have been deleted from the text for readability. Any missing material is indicated with ellipses (...). Also, where words have been missed by participants and the word they intended can be inferred from the rest of the sentence, these have been added, to increase readability. Where material has been added it is enclosed within [square brackets]. All identifying information has been removed to ensure anonymity of participants. Names used in verbatim extracts are aliases.

Table 2**Main themes**

Super-ordinate theme	Subordinate theme
TRYING TO MAKE SENSE IN UNCERTAINTY	Awareness of parent's mental health difficulties: seeing and knowing
	Parent's mental health difficulties enveloped in uncertainty
	Normality v difference
	Trying to make sense: finding a why in the familiar and struggling with the how
TALKING: GOOD IN THEORY, HARD IN PRACTICE	Talking is hard
	Limited direct communication in family
	Talking openly helps
RECIPROCITY AND CONNECTION V FRUSTRATION AND DISCONNECTION	Wanting to care v feeling frustrated by parental mental health difficulties
	Feeling cared for v feeling isolated
	Emotional mirroring of parent
POSITIVE RESOURCES AND ADAPTIVE COPING	The importance of consistent support
	The value of self-sufficiency
	Adaptive coping

1. Trying to make sense in uncertainty**1.1 Overview**

This theme aims to capture how young people understand their parent's mental health difficulties. Aware of their parent's difficulties predominately through observation they expressed considerable uncertainty in relation to them. The uncertainty seemed to derive partly from seeing and knowing their parent's were experiencing difficulties, but not knowing what they were or why. The uncertainty caused some to feel scared and seek to make sense of what was occurring. The process of making sense varied between the young people, with some looking to familiar explanations or linking the difficulties to external events. The extent to which they searched for an understanding seemed connected to where

they conceptualised their parent's difficulties in terms of 'normality' and difference. For those emphasising normality within their family, there was less emphasis on making sense, perhaps because there was less difference to explain. For those seeking to understand how the difficulties came about, there appeared to be a greater struggle to make sense. Those attempting to hold multiple explanations found it difficult to integrate ideas or feel they had achieved a satisfactory understanding. Overall, it appeared the gap between being aware of parent's difficulties and meaning making was filled with uncertainty.

1.2 Awareness of parent's mental health difficulties: seeing and knowing

All the young people had an awareness of their parent's mental health difficulties to some extent. Their awareness seemed to come from witnessing changes in parental behaviour. Alara spoke of noticing changes in her mum after she divorced her dad. She appeared keenly aware of her mum's difficulties, using behavioural signs to judge how she was feeling.

When they first got divorced my Mum was really upset and she used to take a lot of tablets and everything (...) like she used to always cry. (Alara)

Katie recognised the signs of her mum's anxiety through seeing how she looked.

She'll kind of just look quite upset or distraught, like quite just worried. You can kind of tell if someone's worried. (Katie)

Some were particularly aware of the physical aspects of their parent's difficulties. Emily spoke of anticipating her mum's 'fits' by observing changes in her behaviour.

She just kind of stays there, and then she has her fit. She doesn't just have it. Just kind of... I mean she goes quiet, so I know it's probably about to happen. (Emily)

Some participants recalled when they first noticed their parent's difficulties, with often vivid memories of their parents suddenly showing distress. Alara recounted first becoming aware of her mum's difficulties, with a description of her attempting to jump off the balcony. Witnessing her mum's distress and self-destructive behaviour, gave her an immediate

awareness of her parent's mental health difficulties as, although young, Alara understood her mum's intentions.

*My Dad was going and my Mum got really annoyed, and she went outside and she went up to the balcony and told me to wait inside, and I waited and then I went out she put her foot over the balcony, but then my Dad saw and he ran upstairs, but I was holding my Mum. (...). I was really upset, I was scared. (...)
She, she wanted to jump down. (Alara)*

Some young people experienced a sense of knowing about their parent's difficulties, without a clear sense of how, their awareness seemingly emerging simply from living with their parents. Anna described instinctively knowing her mum was unhappy.

I realised, she don't really, like she's not happy with this like place for as long as I've known. (Anna)

Through seeing their parent's behaviour, the young people became aware of their parent's distress, leading some to closely attend to changes in their parent's behaviour to gauge the severity of their mental health difficulties.

1.3 Parent's mental health difficulties enveloped in uncertainty

A striking element in the young people's experiences was the uncertainty that seemed to envelop their parent's difficulties. Many accounts were littered with 'not sure' and 'don't know'. The uncertainty was in relation to various things such as the reasons for and length of their difficulties, the support their parents received and whether other family members were aware.

I interpreted the uncertainty about the length of their parent's difficulties as corresponding to them having gained a gradual awareness of them through observation as opposed to being told directly. Thus I felt their uncertainty was linked to the level to which their parent's mental health difficulties remained unspoken within the family. Emily spoke of her mum's difficulties having been present throughout her childhood and so guessing they were longstanding.

Well as far as I know, since I was born. So it's probably been throughout her life so... (Emily)

Similarly, some expressed uncertainty about everyday events related to their parent's mental health difficulties. Emir talked about helping his mum take medication, although unsure what it was for.

Sometimes, like yesterday she, sometimes she gets tablets for something, but I don't know what for she gets it and I give her water. (Emir)

This highlights how the young people had unasked questions about their parent's difficulties.

Some clearly experienced strong emotions when faced with uncertainty, speaking of feeling scared in response to not knowing what was happening, unable to make sense of their parent's behaviour. These feelings seemed most prominent when they first discovered their parent's difficulties, with the shock of their parent's distress unsettling. Katie, described her reaction to the first time her mum became 'suddenly out of the blue (...) really upset and nervous' as worrying.

I was kind of worried 'cos I didn't really know what was going on, I didn't understand why she was so upset or why she was so distressed. So I was kind of scared. (Katie)

Emily also spoke of feeling frightened when she first witnessed her mum having a 'fit' because she did not understand.

I was kind of scared because I didn't know what was going on. (Emily)

Their words demonstrate how being aware of something without understanding can lead to feeling unsafe. To manage this feeling the young people attempted to make meaning and develop explanations for their parent's behaviour. However, this process of making sense also seemed fraught with uncertainty for some; feeling unsure about the reasons behind their parent's difficulties made it hard to make sense of what they observed. I interpreted their

struggle as showing how incomprehensible their parent's difficulties appeared. Alara's words capture this when talking about her mum.

'Cos she gets upset sometimes for many reasons, not sure why (Alara).

Uncertainty was present in many aspects of the young people's experience with a variety of effects; for some it raised questions, for others it led to guessing in order to make sense. Whilst uncertainty created strong negative feelings for some, the struggle to make meaning was experienced by many.

1.4 Normality v difference

There was an apparent tension for some between acknowledging differences in their family as a result of their parent's mental health problems and viewing their situation as 'normal'. The young people varied in where they positioned themselves on this continuum, with some holding conflicting views simultaneously. Some of them emphasised normality within their family, as shown in Emily's and Anna's words.

It's just kind of like a normal family really. (Emily)

Like relationships, like it's not really changed, she's still the same like. She like, like we're still normal as... (Anna)

I felt this view of a 'normal family' potentially represented a number of things, for example, the limited impact of their parent's difficulties, or a lack of awareness of differences because they had no comparison. Moreover, it may relate to a discrepancy between their everyday experience of parental difficulties and how they imagine mental health problems. As media portrayals and stereotypes of mental health problems are often extreme, they may not recognise their parent's difficulties fitting with this. However, there were also indications it was hard for some to acknowledge differences in their families. Emir, for example, contradicted himself when talking about what was hard about his mum's difficulties, initially indicating he found his parents arguments hard then saying he did not mind them.

There's nothing hard, but they used to argue and I used to tell them to stop arguing and they used to stop. (...) Yeah I didn't mind. (Emir)

Emir's changing view on the arguments he connected with his mum's difficulties seemed to demonstrate a sense of family loyalty and perhaps a desire not to be different, have his family pathologised or stigmatised.

The desire to be 'normal' was articulated by Emily, who compared her mum with other parents, highlighting her struggle accepting the differences her mum's mental health difficulties created, again perhaps indicating the stigma connected to such difficulties.

'Cos sometimes I'm kind of like I'll just wonder, like why can't she just be normal? Like it's kind of annoying. Kind of like, oh ... why can't she just... like all the other parents... all the other children, they don't know that ... they're like they take their parents for granted. 'Cos they're just like normal. Like if she... 'cos she is normal, it's just that little aspect. (Emily)

Katie was also aware of the difference between her mum and others, speaking of how few people experience mental health difficulties.

Hardly any people get this problem, or that I've met, or children, so it's really weird seeing [mum get anxious] happen. (Katie)

The extent to which young people acknowledged their parent's difficulties appeared embedded in their construction of differences and 'normality' within the family. The role of representations of mental health problems appeared important; the everyday reality of parental mental health difficulties was seemingly at odds with cultural stereotypes. For some the tension between acknowledging differences and describing 'normality' seemed born out of a desire not to be stigmatised or seen as different. For others the tension was less apparent, having a stronger sense of either differences existing or not existing within the family.

1.5 Trying to make sense: finding a why in the familiar and struggling with the how

1.5.1 Finding a why in the familiar

Analysis indicated young people sought to make sense of their parent's mental health difficulties by looking to the familiar. Often they connected their parent's difficulties to external factors or events, providing a concrete explanation for their observations. The process of making sense and finding meaning was done largely independently and in relation to the specific behaviours seen.

Relationship difficulties and parental separation were viewed as the precipitating factor by some when asked when their parent's difficulties started. Emir made a direct link between his parent's arguments and his mum's mental health problems, providing him with a definite explanation.

They used to be alright, when they didn't argue, they used to be alright. They started arguing and then that's when she [felt unwell]. (Emir)

Grief was how Hayley and Chris made sense of their aunt's distress following their mum's death and subsequent deaths within the family.

Well first she was crying a lot. But then it's like she kinda like picked herself up. And then she got over it. But then after a few old people died, like my Granddad, and my Grandma had passed away before that. And then like she started going back again, and she came back up. Then her new baby died recently. (Chris)

Physical health and medical explanations were used by some to make sense of their parent's difficulties, with Emily linking her mum's difficulties to diet and medication and Emir to his mum's pregnancy.

I think it depends on if she takes her tablets or not. (...) Sometimes if she doesn't eat, and then takes a tablet, it happens, and she feels sick. But if she eats regularly and she takes her tablet, then I feel like it doesn't happen. (Emily)

She says I can't sleep. Because, I think, because of the baby, because she has some problem. (Emir)

Anna sought to explain her mum's difficulties by environmental reasons.

I think it's the housing, she don't feel comfortable here, like it's a very small place and like that's it. (...) It's the area and like lack of space, because like for instance, not sure, I don't know. (Anna)

What is notable is the degree to which some remained tentative; indicating a sense of uncertainty remained. With their explanations incorporating familiar events and experiences, their meaning making utilised what was observable as opposed to abstract internal factors. Furthermore they tended to hold a simple single explanation for their parent's difficulties rather than develop a more complex understanding.

Katie differed from the others in this, as she attempted to hold multiple explanations for her and her mum's anxiety, incorporating ideas of genetics, bereavement and systemic factors, she looked beyond the familiar.

I think she kind of got it 'cos of her Dad. 'Cos when she was like 6 her Dad died in a train crash so she saw her Mum going all nervous over that, so then she started to develop anxiety. And then from her, I think I got it. (Katie)

People telling me that I might get nervous kind of made me nervous. (Katie)

I don't really think it's coincidental that her Mum had it, my Mum had it, and now I have it. It's obviously something genetic, or something going round in our family. So therefore I think if she didn't have it, then I wouldn't have it. (Katie)

The idea of family transmission comes across strongly in Katie's attempt to make sense of her and her mum's anxiety, with the view people expecting her to develop difficulties prompted her anxiety. There is a clear sense that she holds her mum responsible for her difficulties, hence in seeking a more complex understanding she faced difficult relationship issues.

1.5.2 Struggling with the how

The struggle to understand how mental health difficulties work was most prominent for Katie. Perhaps because of her own experience of anxiety she wanted to grasp what her and her mother experienced but, even though she was given repeated explanations, a proficient understanding remained elusive.

Well a lot of people have explained it to me, told me, you know, what it's about and how it works. But I don't, in a way, I still don't really understand it. (Katie)

I don't understand how something in my mind affects my body so much. (...) I can't ex... I don't understand how... how oh how it was, or how it came about (...) It doesn't really suddenly come on, but it doesn't really edge on slowly. So I... I never really understand how... how suddenly I'm nervous. (Katie)

Emir similarly found it hard to reconcile how his conceptualisation of why his mum was unwell corresponded to her difficulties, seemingly aware her pregnancy was not enough of an explanation.

She's pregnant and ... I don't know, she's only pregnant and she's not feeling well. (Emir)

The young people were less likely to consider how the events and experiences they related to their parent's mental difficulties caused them. For those that sought to understand the how, there was a struggle to reach an adequate explanation, leaving them uncertain.

2. Talking: good in theory, hard in practice

2.1 Overview

There were mixed feelings about talking about parental mental health difficulties. Some directly expressed their reluctance to talk with friends and parents and it became apparent during interviews that some had difficulty talking. Finding it hard to talk seemed related to concern for how others might react and a wish to avoid thinking about what was difficult or uncertain. Similarly, it emerged that the majority of communication about parental mental health difficulties within families was indirect, with young people overhearing things rather than being told directly. Parents' limited talk about their difficulties mirrored the young people, seeming to hinder them from talking. Alongside their reluctance to talk some expected talking would be helpful, informed by professional discourses that letting things out helps. This encouraged one young person to talk openly with their parent which they found helpful.

2.2. Talking is hard

The theme of talking about parental mental health difficulties being hard emerged from both the interview process and young people directly expressing this view. Those appearing to struggle talking in the interview were less likely to directly express that talking was difficult, whereas those seemingly more able to express their experiences tended to say they found talking hard. Within the interview process it was apparent at times young people trailed off when talking about their parent's difficulties, which I interpreted as them finding talking hard. It seemed some things were left unspoken, or could not be verbalised, perhaps because it was painful to acknowledge them.

Well she's, she's not happy about the situation but... (Anna)

Some responses, to questions inviting young people to share potentially difficult thoughts and feelings, gave a further indication that talking was difficult. With repeated expressions of either not knowing or not thinking about events, it seemed talking might be hard because they avoided thinking about their parent's difficulties.

Cassie: What do you remember about that time [when you first became aware your mum wasn't feeling well]?

Emir: Can't think.

Cassie: So you heard them arguing and you'd come and say to them stop because your little sister might get upset. How did you feel at the time?

Emir: I don't know, no, I wasn't thinking.

Some recognised the difficulty they had articulating their experiences, the struggle to talk apparently related to the amount of uncertainty and communication in their family about their parent's difficulties.

I'm not sure, I don't know she doesn't like show, how can I explain it, it's just I know, like she'll say sometimes like, oh I'm not sure, I don't know, I don't how to explain it. (Anna)

It seemed as if some did not have the words for talking about their experience. This is perhaps best highlighted by Anna saying she does not have a name for her mum's problem, suggesting it remains unspoken.

Cassie: How would you describe your mum's problem? Is there a name you call it?

Anna: Not really, I don't really say a name.

Some indicated it was difficult to talk to their friends about their parent's difficulties, opting not to tell them or by referring to supportive services (Young Carers) as a youth club.

When [mum's difficulties] just happens on the street it's like it's embarrassing for me, because what if I see my friends and stuff? And 'cos I don't really tell them about her difficulties, like I don't think anyone knows in my school. (Emily)

I just call [Young Carers] youth club (...) because I know there's a lot of them, loads of people who would ask questions as to why [I go there]. And like if they

don't already know like what's happened, then I'd rather just not go into it.
(Hayley)

The function of not talking appeared to protect young people from being viewed as different. Their wish not to be different is consistent with the developmental stage of adolescence, where peer group conformity is prized as individuals strive to find an identity within their peer group. However, reluctance to talk also seemed connected to how others might react, with the underlying suggestion that others may treat them differently if they knew. This is perhaps indicative of the young people experiencing a sense of stigma about mental health difficulties.

I'll just be embarrassed (...) I don't know, maybe [friends] just kind of not not talk to me, but kind of be self-conscious. They'd be like, "Oh should I say this? Should I act normal? Should I be a bit quiet? Should I be too like bubbly or...?" (Emily)

Some spoke directly about their wish not to talk, indicating the cultural expectation to talk, supported by professionals, does not always match what young people want.

Sometimes you don't always wanna talk. Like I know people say you should like let it out, but sometimes that's not always what you wanna do. (Hayley)

The difficulty broaching the topic of parental mental health difficulties with parents was also articulated; Katie described her reluctance to talk to her mum being partly because her mum did not talk about her difficulties.

I felt really uncomfortable asking her about it. Because it was one thing we didn't really talk... we talked about my anxiety, but we never really talked about her life, or her anxiety. So when I asked her, at first I was a bit scared. (Katie)

The experience of parents not talking about their difficulties perhaps meant the young people learnt not to talk about them too. With a lack of modelling of how to talk about mental health, talking seemed to be internalised as hard. Overall, there seemed to be many factors influencing why it was hard for young people to talk, not wanting to be different, concern

about others' reactions, not having the words to express themselves or experience of their parent talking about it and not wanting to think about it just some of the reasons.

2.3 Limited direct communication in family

The young people's experience of finding it hard to talk seemed in part to mirror limited talking about parental mental health difficulties within the family. When attempting to describe their parent's difficulties some referred to their parent's silence on the subject when justifying their uncertainty.

No she'll like speak to me sometimes just to say like you know, well not speak to me, oh I don't know how to explain it. She wouldn't say things like not directly, not like that but ... (Anna)

Not quite sure actually 'cos she doesn't talk about it that much. (Alara)

As a result of limited direct communication overhearing conversations seemed to serve as an important way to gain information.

It's kind of seeing it. And like my Grandma's always like (...) "You have to eat because... unless you're just gonna start your fit again. So just eat and take your tablet." So it's like kind of hearing about it as well. (Emily)

I was sleeping and apparently my Mum took a lot of tablets (...) I didn't know what was going on, but after like a few years my Mum was talking about it and then I heard. (...) She was talking to a friend and I heard. (Alara)

The potential danger in gathering information indirectly was highlighted by Katie who described her catastrophic sense making when overhearing her parents talking.

My Mum was just like to my Dad, "Yeah I think she's got my problem, I think she's got anxiety." And I didn't really know what anxiety was. (...) And my Mum was like, "Yeah she can't do a lot of things like a lot of kids her age can

do. I'm worried she's got anxiety." And I thought... at first I'd think of it as some sort of disease and like, "Oh no I'm dying." (Katie)

It was apparent that, with young people gaining information about their parent's difficulties through overhearing information, they did not have the opportunity to check out their sense making and were left to cope independently with their conclusions.

2.4 Talking openly helps

Ideas about the benefits of talking emerged from the transcripts, with young people seemingly informed by the professional discourse that talking helps. Holding a positive view of talking appeared to create a desire in some to talk, as demonstrated in Emir's response to being asked why he wanted to participate in the research.

I just wanted to talk, that's all. (Emir)

Similarly Chris spoke of wanting to talk in therapy following the death of his mother and the onset of his aunt's mental health difficulties.

Yeah we just wanted to talk about it. Like sometimes you see them on the television, and you know like you're supposed to talk. And just say your thoughts, and they give you some advice, and you might listen to it come back and they'll see how you are after that. But she just made us play with toys and sit down. (Chris)

Chris' frustration at the therapy he and Hayley received highlighted it had not matched their expectations, which seemed to have been created through the media. Demonstrating that young people's beliefs about what talking should be like are not only informed by family experience, but by multiple discourses.

The idea of talking being helpful was also shared by Alara, who spoke positively about how talking with professionals helped her mum. Again speaking with professionals seemed connected to expectations of helpfulness.

She tells them what she can't tell me or others, and she feels better when she tells something that she kept inside. (Alara)

In addition to talking with professionals, some spoke of the benefits of talking within the family about their parent's problems. Katie's experience of talking with her mum about anxiety helped her feel comfortable, allowing her to find out what she wanted to know; showing that talking openly can be helpful.

I kind of felt like, "Right well I should just go for it. If she doesn't want to speak about it then, that's it, she's your Mum, she's one person, you know, you really shouldn't feel embarrassed about... I mean embarrassed to talk to," so I, you know, I just went for it. And she did answer me. And then after that I kind of felt comfortable about it. (Katie)

Whilst the young people did not talk much about their parent's mental health difficulties with family or friends, they held positive beliefs about talking and had expectations that talking could help. These beliefs seemed informed by the media, professional discourses about the relationship between help and talking and positive experiences of talking.

3. Reciprocity and connection v frustration and disconnection

3.1 Overview

This theme describes the young people's relationship experiences with their parents and their feelings regarding their parent's mental health difficulties. Their caring and protective attitude towards their parents and the resulting responsible roles they adopted was a strong theme emerging from the transcripts. This was juxtaposed with some feeling frustrated and restricted by their parent's difficulties, demonstrating the complexity of the connection between young people and their parents. In addition, there was a clear sense of the young people feeling parented and cared for by their parents, indicating the reciprocal nature of the relationship between them and their parent's resilience in providing valued parenting in spite of their difficulties. Alongside feeling cared for, some felt isolated at times by their parent's

unavailability. Overall these experiences seemed to result in a strong bond between them and their parents with their emotions mirroring their parents.

3.2 Wanting to care v feeling frustrated by parental mental health difficulties

3.2.1 Protecting and caring for the family

A prominent theme emerging from all interviews was the protective, caring and responsible roles the young people adopted towards their families. There seemed to be a desire to look after the family, wanting to give back and ease their parent's difficulties. The following extracts demonstrate this, showing the strong bonds that exist between young people, their parents and families and the sense of reciprocity engendered as a result.

She's my mum and she born me and then I need to take care of her. (Emir)

I just felt bad for her. (...) I just kind of felt like I, all the times that I'd been nervous and I was with her she'd tried to comfort me, so this was the one chance I'd got to try and comfort her and, you know, try. (Katie)

Some cared for their families by helping around the house and looking after siblings. Their caring seemed connected to their attentiveness to their parent's needs both now and in the future.

I have to do more, to help her, because sometimes she doesn't feel well, help her with cleaning and cooking sometimes, not much cooking but cleaning, like I have to be nicer to her, I have to be like, I'm not allowed to be rude to her that much cause then she gets upset really quickly. (Alara)

Just help around the house and that's it really. (...) Just normal like cleaning and may be helping my sisters, like looking after my sisters and helping. (Anna)

I dunno what's gonna happen really in my life, but I might have to stay (...) to help look after my sister. (Emily)

It was apparent that some assumed responsibility for their parent's wellbeing by providing for them, considering their needs and helping them when upset.

Sometimes I'm like worried to leave her alone, at home when I'm going to school, 'cos she gets upset sometimes for many reasons, not sure why, (...) even like when I went to school I used to always think about her. (Alara)

At nighttimes she can't sleep by herself. And we'd get up and say why you can't sleep and then we can't sleep as well. (...) [Mum] says I can't sleep. (...) Then I say try and sleep, try and sleep. (Emir)

For Emir, the eldest sibling, this role was recognised by his sisters, who looked to him for reassurance and to help their mum. Emir took a caring and protective role towards them, thinking of their needs and being there when they needed him.

Sometimes my little sister comes into my room and says my mum's not feeling well, 'cos she comes and says it. (...) She says 'mama, go and check mama'. (...) She used to cry when my mum didn't used to sleep (...) I was saying don't cry nothing will happen, you don't have to cry. (Emir)

In addition to a desire to care for the family, were parent expectations for them to behave in a certain manner, limiting demands. This need to support their parents was accepted by the young people who spoke of censoring their behaviour to help.

She tells me I'm not supposed to upset her a lot, things like that. (Alara)

Say sometimes when she wants us to be quiet or be good when she's not feeling well. (Emir)

3.2.2 Frustration and restriction

Alongside the desire to care for their parents and assume roles of responsibility, some acknowledged frustration at the restrictions of taking on such roles. At times the sacrifices made as a consequence of placing their parent's needs before their own were experienced as annoying.

It's not always good though, 'cos we have to collect our little brother [from school] (...). It's annoying. (...) When you've got something planned like going to the library or something, like you've gotta cancel it. (Hayley)

When I think about it I'm just like, "Oh, why did my Mum have another baby?" (...). And my Grandma's kind of pissed off as well (...) so now my Grandma's gonna have to help my Mum look after [the baby]. (Emily)

Alara's frustration was clearly linked to being prevented from doing what she wanted when her mum became emotional. I interpreted this as a common adolescent reaction to feeling restricted. However, I felt that, because being told what to do was incongruent with the level of responsibility she assumed for her mum's wellbeing, her experience of frustration was perhaps more intense.

Don't like [it] when [my mum] gets annoyed really quickly, and when that happens she doesn't let me go downstairs to my friends house or do certain things I want to do. (Alara)

She shouts at you and if she's annoyed with someone else she takes it out on you, yeah that's what she does. It's annoying. (Alara)

Whilst some identified feelings of frustration, others did not express any. This may be because they did not encounter restrictions, or perhaps they found it difficult to talk about or view their parent's difficulties negatively. This seemed the case for Katie who was ambivalent about the restrictions her mum's anxiety placed on her; interpreting her mum as being protective but also recognising her mum's contradictory behaviour prevented her from doing what she wanted.

My Mum is kind of nervous of getting sick. So if one of my friends have just been sick, then she doesn't want me to go and see them in case they're ill. Which in a way is good for me, because then I don't get ill. (...) But (...) my Mum's always saying, you know, even if you're nervous you just have to do it. Which is weird because I'm like, "Well I want to go see [my friend.]," but, "You can't do it 'cos I'm nervous." (Katie)

Although frustration was less prevalent than a desire to care, it is an important aspect to be aware of. The young people that experienced frustration had to integrate this with their desire to care for and protect their parents. In addition, those experiencing ambivalence about the restrictive nature of their parent's difficulties had to manage this alongside their wish to comfort their parent, highlighting the complexity of the young people's relationship with their parents.

3.3 Feeling cared for v feeling isolated

3.3.1 Feeling cared for by parent

A salient theme emerging from the transcripts was the young people's experience of feeling cared for by their parents who, in spite of mental health difficulties, showed resilience by continuing to meet their children's needs. The warmth and affection for their parents was clear when they talked about what they valued about their relationships, again demonstrating the bonds existing between them.

The young people shared how they enjoyed their parent's company, confided in them and looked to them for guidance. Some clearly expressed their view of the relationship as equals, seeing their parent as a friend. I interpreted this as perhaps a consequence of the reciprocity within their relationships or signifying a natural development now the young people had moved into adolescence.

We went shopping like last weekend and I had a good time, you know, we just went and we had a laugh about, you know, funny ugly clothes or whatever, and it was good. We just had a nice chat like we were friends not, you know, mother and daughter. (Katie)

In a way she's like my friend because she gives me, she tells me what I can do, and I can go, she gives me advice and I can just go tell her anything, that happens between anyone and me. (Alara)

Amongst the young people's descriptions was the sense their parents were doing their best trying to maintain a familiar routine, signifying their resilience and resources in the face of difficulties.

Since she tries to keep everything normal there's nothing like, I don't think I'd lose anything [if mum didn't have difficulties], I know she'd still be the same. (Anna)

She gets on and does what she has to do, like you know cooking and stuff. (Anna)

My Mum kind of got on with what she'd got on to do and needed to do. (Katie)

She's like a normal parent really, there's nothing wrong with her really, if I think about it. (Emily)

Another important aspect of the young people's experience was their parents showing interest in their development and providing boundaries for them, as this symbolised caring. The significance of this is articulated by Chris in the following extracts.

She acts like our Mum and stuff, like we have to ask for stuff, we have to... say when she tells to come back home like, she isn't just like one of those parents that say, "Oh yeah you can do whatever you want." It's just that you speak to her on a level. (Chris)

Our aunt comes [to parents evening], and like then you have something to show her, something that you feel proud of, 'cos you know someone that you love and care about is there to see what you've done. (Chris)

The young people's positive experience of continuity in being parented and cared for by their parents in spite of mental health difficulties was noticeable across their accounts and brought forth the resilience and resources amongst their parents.

3.3.2 Feeling isolated, parent unavailable

Alongside feeling looked after by their parents, some experienced their parent as unavailable at times. This left them feeling disconnected from their parents, unable to turn to them for support, as illustrated by the following extract.

She used to be miserable all the time, and she didn't want no one to come and see her and things like that and she wanted to stay alone from everyone and she was always sleeping and taking sleeping pills and sleeping, and I got really upset 'cos I felt alone. (Alara)

For some there was a fluctuation in the availability of their parent, leaving them uncertain about how their parent would respond. The unpredictability of their parent's availability appeared to make times when their parent was available more valuable.

Well when it's just me and her chatting and, you know, we're getting on, it's been quite nice 'cos I feel like there's somebody else there who understands it. But then when it's not me and her, or when we're having an argument, then it's not really that nice, because it's kind of like more like, you know, in an

obnoxious way. (...) Like, you know, "This... I have this problem, I did this, you know, and you have to find your way." (Katie)

She started going back again, and she came back up. Then her... her new baby died recently. So she was just like a bit... gone a bit. And then she came back. (Chris)

Not feeling listened to was another way in which young people experienced their parents as unavailable. For Katie this was particularly hard to grasp as she knew her mother experienced similar difficulties to her, yet she found she was neither empathic nor supportive at times.

Usually we have arguments about [my anxiety] 'cos I miss a lot of class because of it. So that's how we talk about it, so we argue a lot. And sometimes obviously when I go like that she doesn't understand, but then again I know that she does understand. (Katie)

She used to just take [our cousin's] side always, and never used to hear our side. (Chris)

The threat of abandonment was present in some young people's experiences; particularly for Alara who, having seen her mum attempt to jump off the balcony when she was younger, was frequently threatened with abandonment, being told she would be sent to her Dad's house. I interpreted Alara's aversion to being sent to her dad's as a mixture of not wanting to be left by her mum and feeling responsible for her mum's wellbeing, concerned about what might happen in her absence.

Sometimes when I annoy her she says I'm going to call your Dad so he comes and picks you up, when I don't like staying in my Dad's house. (...) I get annoyed and she's like I'm going call him now and I say please no, I don't like staying with my Dad. (...) And then she says either do this or I'm going to call him, she's like this is your last chance and every time I do something she's always says this is your last chance. (Alara)

It was apparent that, even though all the young people felt parented and cared for, some had simultaneous experiences of their parents being unavailable, producing feelings of isolation whilst making the good times seem fragile and more valuable. This is an important aspect of experience to be mindful of and again demonstrates the complex and changing nature of the young people's relationship with their parents.

3.4 Emotional mirroring of parent

The connection and reciprocity between the young people and their parents was also seen in the description of their feelings. For some their emotions mirrored their parents, as they responded to their parent's emotional states with similar emotions. This occurred in relation to both their parent's positive and negative affective states, with some looking to their parents to know how to feel.

Anna: Well she's, she's not happy about the situation but...

Cassie: And how do you feel about the situation?

Anna: The same.

Some of the emotional mirroring seemed connected to concern about what might happen when their parents were distressed. With the young people perhaps aware of the impact of their parent's distress, they too became upset and worried.

When she starts crying and she can't control her breathing. Yeah and then I get upset as well. (Alara)

I'd feel sad 'cos sometimes people say something's going to happen, that's why. (...) I might sometimes worry, that's it. (Emir)

Some of the emotions felt by the young people in connection with their parent's mental health difficulties seemed to be felt on their parent's behalf; the strength of their bond leading them to attempt to shoulder some of the difficult feelings for their parents.

Like I get annoyed with the people who did actually get [my mum] upset. (Alara)

Just feel upset for [mum]. (Anna)

Some directly connected their happiness to their parent's, predicting they would be happy if their parent no longer experienced mental health problems. This again highlighted the connection between parents and young people, the strength of their bonds, but also the dependence of their feelings on things beyond their control.

It was nice because like my Mum was having fun and when my Mum has fun I get really happy. (Alara)

I don't know, I feel... like she's happy I'll be. (Anna)

The mutuality of emotions is described by Alara as she connects her feelings and behaviour to her mum's in a cyclical process.

'Cos if I answer her back a lot and then she gets really upset, but if I be really nice to her she she's nice to me as well and does what I want and doesn't get annoyed at me. (Alara)

Overall, emotional mirroring seemed to be born out of a desire to protect and care for their parent, the strength of their connection and concern for the consequences of their parent's distress. Whilst in some ways it was positive, demonstrating their close relationship and attachment, the drawbacks were that the young people might frequently experience negative emotional states and feel a lack of control over their emotions, due to dependency on their parent's affective state.

4. Positive resources and adaptive coping

4.1 Overview

A further theme emerging was the adaptive coping and positive resources the young people developed as a result of their parent's difficulties. Finding comfort in consistent support from others, they also felt some support did not go far enough. Some positively valued their self-sufficiency, developed in response to their parent's difficulties, seeing the benefits in accepting their situation and continuing to work towards what they valued. Coping overall appeared to be a personal learning experience for the young people, who found diverse and adaptive ways to manage difficult feelings resulting from their parent's difficulties.

4.2 Consistency of support important

4.2.1 Support provides a sense of belonging

A key factor in the young people feeling supported was the presence and acceptance of others and the sense of belonging it created. Support was gained from a variety of sources, including family, friends and services. Siblings had an important role for some, sharing experiences and providing a break from their parent's difficulties.

'Cos like there's some stuff, like we had an options evening yesterday, that you could bring your parents to, but [Chris] went by himself. And I don't know where [our aunt] was, but I came (...) too... (Hayley)

*[When I try to take the sadness out of my head I] play with my little sister. (...)
Talk with her, the other one, the big one, talk with her. (Emir)*

Hayley described how her sister would step in and help their aunt see their side, demonstrating how siblings would try to look out for each other.

*[Our aunt] used to just take his side always, and never used to hear our side.
And then our older sister, like she said, "Well you're always taking [our*

*cousin's] side," and she explained like the situation, explained everything.
(Hayley)*

Similarly, others were supported by family members stepping in to care for them. Emily's grandmother, for example, provided Emily with a secure and consistent attachment. For Emily this was an advantage her peers did not have. She felt her grandparents' presence brought the family closer together, providing Emily with a strong sense of belonging.

[Mum and I] like we're close, but not as close as my Grandma. (...) My Grandma was always at home, so she was the one that really looked after me, if I think about it. (Emily)

My family's kind of tight and it's like, I dunno, maybe just 'cos my Gran was there or something, and 'cos my Grandma and Granddad are still alive. (...) It's really an advantage for me, because some of my friends, they don't... they've never known their Grandma and Granddad. (...) It makes our family more tighter and together. (Emily)

The presence of family was evident in some transcripts, their support seen as helpful by the young people. The wider family seemed to provide some relief from feeling responsible for their parent's well-being and space to feel happy.

Yeah, it was most of the time my Dad's and my Mum's family was always coming. (Alara)

[My dad's sisters] cook the food when [mum's] not feeling well and look after her. (...) It's good, I feel good, someone is helping my mum. (Emir)

For some family friends provided a similar role. The presence of Alara's mum's friends allowed Alara to relinquish responsibility for her mum's wellbeing temporarily as she trusted they would ensure her mum was okay.

I didn't want to leave her at home by herself either her friends used to come. (...) They used to just come over to sit with Mum so my Mum forgets things for a few hours and was alright. (Alara)

The response of friends was also appreciated by those who felt able to tell their friends about their parent's difficulties. This seemed particularly valued as the young people indicated others might not be as understanding or supportive.

It's actually nice 'cos like they don't, some people, if it were others, they would say what's wrong with your Mum and all that and they would always question that but my friends aren't like that, if I don't want to tell them something they don't always ask and if I want to tell them they listen to me. (Alara)

Support provided by services was viewed positively by some, with the opportunities provided and consistency of support seemingly significant aspects.

I think [Young Carers is] good because it gives us stuff to do after school. (...) It's given us better opportunities as well. (Hayley)

[Young Carers is] like another place to go, so I just like it. Yeah 'cos I've been here since... I remember, 'cos I know I'm a really old member. Although I don't attend a lot, like a lot of the things, but I will attend some, but like there's a few friends of mine, we've been old members. (Emily)

I have people there for me to talk to, and I know that I have a lot of people that care enough to go through this for me. (...) I just know that there's a lot of people that love me and that are giving up a lot of their time and go through a lot of trouble to make sure that I get a good education. (Katie)

Support from family, friends and services served a number of different functions, allowing the young people to feel accepted and not alone, as well as providing some relief from feeling responsible for their parents. An important factor was the feeling there was someone there for them when needed, thus consistency of support and a sense of belonging seemed central to their positive experience of support.

4.2.2 They don't do enough

The importance of consistency of support was emphasised when young people shared the view that sometimes family and services do not do enough to help their parents. This is particularly apparent in Hayley's description of her family not being around much, leading her to no longer view them as family.

No, there's people who are meant to be family, but only come at the time, and then after a while you don't see them, like that. When people ask me about my family, I kinda only talk about us lot, and the cousins that we speak to sometimes, and that's it really. (Hayley)

Similarly Alara described how the family did not always consider her mum's needs, concluding they did not care about her mum. The disappointment she experienced is noticeable when she talks about how her family just visited for a short while, providing only temporary relief from her sense of isolation.

My Mum was going to go to (...) and... like [the family] never even asked her if she has any money or if she needs anyone to taking to like the airport if they want, they didn't even ask her nothing, and they didn't even say do you need any help looking after Alara or do you need any money, and my Mum got annoyed and she didn't talk to them for one year. (...) My Mum got annoyed because they didn't even care about her. (Alara)

Whenever they came to our house they just sat for half an hour and they went, and I used to get happy when they used to come because we had people in the house but when they went my Mum just went back to sleep again. (Alara)

Hayley's words express how a lack of consistency in professional support is similarly unhelpful, leaving her to question whether services are helpful.

She's had a few counsellors and stuff, and they haven't really helped because she's getting one after another, and right now she doesn't have one. So I don't think they're helping. And when people look at families that's grieving they keep

saying, “Oh they need a counsellor or a social worker” and all of that, and they’re not helping. (Hayley)

Support from family or services that was not consistent or available enough was viewed as unhelpful and uncaring. Efforts to help which were brief or only related to times of crises were not seen as good enough.

4.3 Self-sufficiency valued

A positive view of self-sufficiency was particularly compelling in the experiences of young people accessing Young Carer’s. Viewing their independence and ability to look after themselves as advantageous, taking responsibility for themselves was normalised for them, as demonstrated by their expectations of when people should start taking responsibility.

Because I’m 14... well 15, and I’ve already got a life, like I know what I’m doing, I’m a teenager so it’s like I can look after myself. (Emily)

[Our cousin] has a responsibility, he’s gonna be 7 soon. So he’s gonna have to do some work as well. ‘Cos we wash up and do our clothes because we know that... You can’t just leave it like some people, yeah, they just leave it for other people to do. But we know how to do it ourselves, we can look after ourselves. (Chris)

The acceptance of self-sufficiency as the norm is emphasised in Hayley and Chris’s words about their reaction to discovering others did not have the same skills. Their positive view of the skills they acquired living with their aunt is apparent as they explain there is no need for parents to do so many practical tasks for their children, when they are capable themselves.

Well you don’t actually realise that you’ve learnt it, it’s just like the only time that you realise is when you hear someone saying like, “I don’t know how to wash my own clothes,” or... I’ve got some friends that their Mum cleans their room, does their clothes, makes them breakfast and whatever. And it’s like they don’t need it, ‘cos when they live out they’re not gonna have those skills for

themselves. Even if they start now, like we're still gonna have the advantage, 'cos we started far younger than them. (Hayley)

I thought everybody would have known about that. I just thought that it was their rooms, they don't do themselves and the ironing. I didn't know they didn't know how to do like the washing machine or wash up or do anything like that. (Chris)

Chris emphasises the benefits their self-sufficiency will afford them in the future.

In a way it's good because we're eventually gonna have to do it. And we know people that doesn't know... (...) When they're older they're gonna find it hard. Because how are they gonna cope with living they'll be like, "How do I do this washing?" (Chris)

Self-sufficiency is viewed as an important resource they have as a result of their parent's mental health difficulties. Developing their independence skills in practical tasks seemed to occur naturally whilst growing up, such that they viewed it an ordinary part of life, speaking with pride that they had skills their peers did not.

4.4 Adaptive coping

The young people coped with the experience of living with parental mental health difficulties in a variety of ways, for example through distraction, acceptance and doing what they valued. Some viewed coping as a personal process that involved learning to live with things and adapt over time. This was informed by their observations of their parent's attempts to cope. Hayley's words show she believes the pain of losing someone does not go away, but people can learn to cope over time.

It's not necessarily that [our aunt's] got over it, it's just like she's learning to cope with it, 'cos she knows that they ain't coming back. (...) it's just that like you kind of get used to it. (Hayley)

Similarly Katie recognised that coping involved learning, takes time and could be enhanced.

I don't really think I've learnt anything so far, but I think I will learn how to cope with it better. (Katie)

Amongst the cognitive coping strategies used were acceptance of difficult thoughts and situations. This seemed a positive and adaptive approach to managing as it allowed the young people to move on and do what they wanted, preventing them from getting caught up in a cycle of escalating negative feelings.

It's just like little [worry] thoughts, it's not like a long thought where I'm just in the room just thinking and thinking for hours, just little thoughts when it does happen. (...) I kind of... it's not as if I push it to the side, but I'm just like, "Oh whatever," and just kind of do whatever, and I'll sort of do it. (Emily)

I'm not really thinking about it, I'm just kind of seeing what's just gonna happen. (...) I thought, "What's the point of thinking about it? Because I dunno what's gonna hold the future." (Emily)

Well we all have our different ways of coping with it, all of us. I'm not really sure how to cope with it, I just, yeah, you know, write something or thinking and just like if everything is quiet you just think about it. Yeah, you know, it's like... you're kind of forgiving yourself. Like you're feeling like you're forgiving yourself for blaming yourself ... or something like that. So you kinda it's releasing all the grief. So you don't feel that way anymore, kind of. (...) It makes you feel more... kinda more because you've realised that you can lift up the sadness so you can get on with stuff. That's like the easiest way to do... it's not really a technique. (Chris)

Another cognitive strategy used by some was self-talk. This was used intuitively by Katie to reassure herself things would be okay when she felt nervous, although she found it only slightly helpful.

When I'm nervous I just say, "You're fine. Nothing's going to happen to you, you're fine." [It doesn't make] really much of a difference, I just do it instinctively I suppose. (Katie)

Similarly, Emir used self-talk to try and calm himself down when angry, recognising the importance of taking a step back from situations where anger can escalate.

When I'm angry I do something bad I try and calm down, count to five and then calm down. (Emir)

Distraction was used by many to cope with difficult feelings in relation to parental mental health difficulties; the need to escape apparent in Emir's words.

Sometimes, sometimes I try and take it out my head and do something else. (Emir)

Amongst the activities young people engaged in to distract themselves were playing, listening to music and sleeping. The benefits of distraction seemed linked to their wish to contain their difficult thoughts and avoid getting into a negative cycle of escalating difficult feelings.

Go outside, play, play football and come back. Go over the park. (Emir)

I usually just you know, shout and just go 'grrrrr' and then just kind of... and lie on the bed and listen to music or something. (...) That's my usual way... or I sleep. (Katie)

I come in here either sit down or listen to music (...) Just to get my mind off it. (Alara)

Overall it appeared that the young people had learnt their own ways of managing their difficult emotions, with some learning that coping is a process built up over time. Their resilience was evident from the adaptive strategies they developed. Whilst some used cognitive strategies to accept the difficulties and move on, others found distraction a useful way of providing space from difficult feelings. In this way they managed to avoid a cycle of escalating negative feelings.

DISCUSSION

In this section the findings are considered in relation to the research question, existing theory and literature. The potential clinical implications, methodological issues and areas of future research are discussed, in addition to my reflections on the research.

How adolescents experience their parent's mental health problems

The process of searching for meaning

This study found that young people are aware of their parent's difficulties through '*seeing and knowing*' and gain information indirectly by overhearing conversations and witnessing changes in their parent's behaviour. This is consistent with Ablser's (1999) observation that children are acutely sensitive to what goes on around them, reacting to changes in parent's mannerisms, facial expressions and mood. Similarly, it supports Garley and colleagues' (1997) finding that young people recognise the signs of their parent's mental health problems, which contextualises and gives meaning to their behaviour. Relying on picking up information over time, indirectly and through observation are important factors highlighted in previous research (Cogan *et al.*, 2004; Riebschleger, 2004). Totsuka (2008) has referred to this as gaining experiential knowledge, contrasting it with informational knowledge, which either validates or contradicts young people's experiential understanding (Totsuka, 2008). This study, indicating reliance on observation to gain information about parental difficulties, lends support to the idea emerging across the literature that this is how parental mental health difficulties become recognised.

Young people's uncertainty and confusion surrounding their parent's mental health problems was prevalent in this study; they felt scared and worried, not understanding their parent's difficulties. This has also been acknowledged by other researchers. Aldridge and Becker (2003) described how young carers were information poor, whilst Handley and colleagues (2001) also found young people expressed confusion and uncertainty about parental difficulties. Likewise, Meadus and Johnson (2000) identified young people as struggling to make sense of their parent's difficulties, due to a lack of knowledge and understanding. There is a frequent message within the literature that enabling young people to understand

parental difficulties can enhance resilience (Falkov, 1998; Place, Reynolds, Cousins & O'Neill, 2002), this study adds further support for this, given the difficult feelings uncertainty and confusion can produce.

In terms of making sense of parental mental health problems, the literature suggests there is a tendency for young people to develop false beliefs about their responsibility and blame when they lack information (Kelly, 1999; Place *et al.*, 2002). Making best guesses based on limited information creates the opportunity for negative and unhelpful meanings to be constructed. The capacity to generate coherent and constructive meaning and make sense of emotional events is thought to be an important contributor to emotional regulation and integration, which can have profound implications on a young person's well-being and development (Oppenheim, 2006). Interestingly the findings from this study did not indicate that young people developed beliefs of blame regarding their parent's difficulties. Instead they seemed to focus on external factors to understand their parent's distress. This finding is consistent with Cogan and colleagues' (2005) research that found children often give social and environmental reasons for mental health problems rather than psychological or medical, locating roots of distress in the external environment. Likewise, Garley and colleagues (1997) indicated that illness attributions amongst children of parents with mental health problems were numerous, including biological, environmental and difficult childhood experiences as explanatory factors. This study suggests that, whilst there is the potential for young people to make sense of their parent's difficulties in a negative way, there is great diversity in their sense making and external factors are likely to be involved.

Ambiguity about talking

Young people's difficulty talking about their parent's mental health problems was apparent across the interviews. This finding echoes Polkki and colleagues' (2004) research which reported young people's non-verbal communication indicated they found talking difficult (Polkki *et al.*, 2004). Many have acknowledged recruitment difficulties in accessing this population, possibly relating to young people finding talking hard (Aldridge & Becker, 2003; Handley *et al.*, 2001; Stallard *et al.*, 2004). In this study the difficulty talking about parental problems seemed related to limited experience of talking, fear of stigma and a wish not to think about what might be difficult. Similar processes also appeared to influence conceptualisations of the 'normality' of parental difficulties, hence the two findings are

considered simultaneously. Experiences of stigma regarding parental mental health difficulties have been found in previous research; preventing young people from talking to others and avoiding acknowledging their parent's difficulties (Aldridge & Becker, 2003; Armstrong, 2002; Cogan *et al.*, 2005). Yuen (2007) has related the reluctance to talk about things construed in modern discourse as 'bad' to the passive position it places young people in, eradicating their sense of agency. Therefore viewing the family as 'normal' may be protective and strengthen young people's sense of agency, suggesting why acknowledging and talking about parental difficulties may be hard.

Also apparent in this study was the gap between the experience of parental mental health difficulties and what they are imagined to be like, which appeared to influence where young people positioned themselves in terms of 'normality' and difference and how easy they found talking. The role of the media in influencing young people's understanding about mental health was hypothesised, as research shows only a few are able to recognise that the media can misrepresent mental health (Cogan *et al.*, 2005). This again points to how stigma may be implicated in young people's experiences of parental mental health problems and how difficulties talking may be perpetuated by societal attitudes in Britain.

This study found that young people's limited talk mirrored their parent's limited talk. Young people appeared to experience their parent's silence as hindering, with some directly referring to how it prevented them talking. This is consistent with the recognition within the literature that there is sometimes a code of silence within families about parental mental health problems (Absler, 1999; Devlin & O'Brien, 1999; Focht-Birkerts & Beardslee, 2000; Kelly, 1999; Place *et al.*, 2002). Stallard and colleagues (2004) reported that a number of young people said no-one had spoken to them about their parent's difficulties. Likewise, adults reflecting on their experiences of growing up with parents with mental health problems described learning the necessity of keeping it secret, internalising the silence of others by not enquiring about their parent's difficulties (De Silva, 1999; Hinshaw, 2004). With silence a core theme permeating their experience they formed their own views of their parent's difficulties and learnt parental mental health was "an issue too dangerous to touch" (Hinshaw, 2004, p.409). Focht-Birkerts and Beardslee (2000) believe family silence is maintained by the parallel processes of children learning to keep quiet to accommodate their parent's unspoken needs, alongside parents feeling their distress is toxic and distancing themselves to protect their children. Similarly, Oppenheim (2006) suggests that when

parents avoid discussions around emotionally difficult topics children may be left with little capacity to integrate their emotional experience and be ill-equipped to cope with similar experiences in the future. Hence the need for children to be given overt permission by their parents to voice their own fears, anger and disappointment is advocated, in order to break the destructive cycle of mirroring parental withdrawal (Focht-Birkets & Beardslee, 2000). The indication from this study that young people's struggle to talk can represent a family pattern is therefore helpful as it illuminates how talking may be facilitated in clinical practice.

Demonstrating the complexity and contradictions within this area, young people in this study expressed mixed views about talking. Some held positive beliefs about the benefits; some clearly stated they did not wish to talk. Stallard and colleagues' (2001) research reported a similar finding; others have highlighted young people's reluctance to talk directly to parents or professionals (Fudge & Mason, 2004; Garley *et al.*, 1997). Overall, these findings seem to represent young people's contradictory positions about talking. Moreover this study develops understanding about the complex factors involved; with stigma, cultural beliefs and taboos, the tension between 'normality' and difference and family patterns some potentially key aspects.

An important layer in young people's experiences is that some view talking about their parent's difficulties positively. In this study some felt talking was helpful, enabling understanding and relief of difficult emotions. This supports Cogan and colleagues' (2005) finding that young people who received information about their parent's difficulty found it helped them to better understand and cope with their family situation. Moreover, it fits with Oppenheim's (2006) view that open, empathic and well-organised dialogues between parents and children about difficult events can help children develop a coherent narrative with a meaning facilitating coping and development. Furthermore it corresponds to the aim of preventive work carried out with families with parental mental health difficulties to develop a shared meaning for the family through linking cognitive information to family members' individual and collective experiences (Place *et al.*, 2002). Hence, despite the many factors that might make talking difficult for young people, it appears there are positive benefits to be gained from supporting dialogue about parental mental health difficulties.

The finding that consistency is central to young people's positive experiences of support is useful as it may help them to develop trust and overcome their ambiguity about talking.

Young people in this study valued ongoing support from family, friends and services, with a sense of belonging seemingly an integral factor. The importance of support is emphasised repeatedly in the literature (Fudge & Mason, 2004; Garley *et al.*, 1997; Lancaster, 1999; Marsh, 1998; Maybery *et al.*, 2005; Parrott, Jacobs & Roberts, 2008; Pokki *et al.*, 2004; Thomas *et al.*, 2003). Similar to this study, Aldridge and Becker (2003) found young people often have good relationships with relatives and form important attachments with other family members, augmenting feelings of security and well-being. Likewise, good social support and connectedness are suggested to promote resilience, with young people's siblings often providing close reliable support (Maybery *et al.*, 2005; Polkki *et al.*, 2004). The closeness in families resulting from pulling together to look after each other, as described in this study, is a further aspect that has been recognised (Thomas *et al.*, 2003). The role of community support has also been highlighted as helpful (Parrott *et al.*, 2008; Place *et al.*, 2002). Again, consistency of support is recognised as a vital aspect in community interventions. For example, drawing on attachment theory, the organisation *Newpin* aims to provide stable, consistent and available support to families with parental mental health difficulties over a three year period, offering an object of attachment (Lederer & McHugh, 2006). This study therefore adds to the growing body of research demonstrating the importance of support, and further promotes the role of consistency and belonging within this, which could have helpful implications for how services can support young people.

Managing the tension between conflicting feelings

The finding in this study that young people take on caring roles towards their families has previously been shown (Aldridge & Becker, 2003; Garley *et al.*, 1997; Maybery *et al.*, 2005; Meadus & Johnson, 2000; Thomas *et al.*, 2003). However, researchers have been divided as to whether taking on a caring role indicates parentification and role reversal (Garley *et al.*, 1997; Handley *et al.*, 2001), or whether it signifies reciprocity that is distinct from parenting (Aldridge & Becker, 2003; Thomas *et al.*, 2003). A powerful element in the young people's experiences in this study seemed to be a desire to care; adding weight to the idea that caring seems to be a function of the strong parent-child bond, moving away from the idea of parentification. As reciprocal caring may fit better with cultural norms in collectivist cultures, it is useful to consider this finding in terms of the young people's cultural backgrounds. Marsh (1998) has indicated a balance between young people honouring commitment to their parent and feeling free to live their own lives is important. However,

Gopfert (1996) emphasises that it is the right of children to deal with worries about parent's mental health by caring for them. Moreover, Aldridge and Becker (2003) posit that role adaptations tend to be episodic and are experienced as distinct from filial relationships that continue even when parents are distressed. This study supports these latter findings, indicating that caring can be a positive and natural element in warm and loving relationships with parents with mental health difficulties.

Nevertheless, frustration in relation to parental difficulties and caring was also evident in young people's experiences, with restrictions to personal freedom experienced as 'annoying'. This is similar to what has previously been identified in some of the literature. Garley and colleagues (1997) found that taking on caring roles could result in conflict between young people and their families. Additionally, Smith (2004) suggested some young people felt angry and resentful of disruptions to their relationship with their parent, such as their parent's unpredictable behaviour, and ineffective attempts at limit setting. However, it is suggested that gradual de-idealisation of parents during adolescence is helpful in allowing individuals to explore their emotional and cognitive autonomy and, if in the context of an emotionally supportive parent, will promote attachment security (Allen *et al.*, 2003). Hence the finding that some young people may experience frustration in relation to their parent's difficulties may partly represent a broader developmental process. This illustrates the importance of holding in mind contextual factors, demonstrating the complexity in young people's experiences, with frustration sometimes felt alongside a desire to care for parents.

The finding in this study that young people continue to feel parented is significant because of the role positive parenting is thought to play in resilience (Falkov, 1998). In a recent research review (Parrott *et al.*, 2008) parental love, boundary setting, listening, praise and acknowledgment of mistakes were identified as possible foundations for young people's resilience. In this study young people's experiences of parents maintaining normal routines, being interested and available to support them were particularly salient, with the warmth towards their parents evident in their words. Aldridge and Becker's (2003) research with young carers was similar in that young people construed their relationships with their parents as positive, with quality and continuity key features. Fudge and Mason (2004) found that amongst the strengths of families with parental mental health problems was the children's experience of unconditional love and positive parenting. Hinshaw's (2004) account of growing up with his father with bipolar disorder further emphasises this, as he describes the

emotional support his father provided, answering his questions and comforting him from nightmares. Likewise, professionals working with parents with mental health problems indicate that parents often display tangible warmth when talking about their children (Place *et al.*, 2002) and can be just as loving as other parents (Rutter & Quinton, 1984). Thus this study adds to the growing recognition that young people can experience their parents as devoted to their needs in spite of their mental health difficulties.

However, the sense of isolation experienced at times by some young people in this study is important to acknowledge, with them sometimes feeling disconnected from their parents and having to negotiate fluctuations in their availability. This is consistent with young people's experiences of their parent's as unavailable, as expressed in other research (Meadus & Johnson, 2000; Riebschleger, 2004). Meadus and Johnson (2000) described how young people felt a loss of parenting resulting from their parent's difficulties, whereas Riebschleger (2004) highlighted that young people constructed their parent's difficulties in terms of them being less attentive and more withdrawn. Handley and colleagues (2001) reported some found separation from their parent due to parental hospitalisation painful; suggesting that continuity in relationships is valued. This study appears to build on previous research, again indicating the complexity of young people's experiences, with some feeling isolated whilst simultaneously valuing the care and love they feel from their parents. Thus it seems parents are not experienced as either always available or unavailable and such polarised views are unwarranted.

The finding that young people's emotions can mirror their parents again signals their connection and strong bonds. The concept of emotional mirroring fits with attachment literature on affect attunement; the process in which two people mutually create, match and share their affective states (Stern, 1998). This is usually discussed in relation to how parents attune to their children's affective states, enabling children to develop internal representations of feeling states (Fonagy, Gergely, Jurist & Target, 2002; Stern, 1998). However, in this study it seemed the young people often attuned to their parent's emotions, with unclear consequences. Increasing the likelihood of negative emotional states, it also seemed connected to a positive desire to protect their parents. Hindle's (1998) case study of an adolescent living with his mother experiencing mental health difficulties depicts this. Drawing on a psychoanalytic framework Hindle (1998) described how Kennie's close relationship with his mother, attachment and loyalty meant he was inextricably involved

with her and could not differentiate his own thoughts and feelings from hers. Young people's ability to discern themselves from parents' emotional experiences is highlighted by Polkki and colleagues (2004) as fostering resilience, indicating there might be negative consequences of emotional mirroring if it impedes young people's ability to separate their experience from others. Whilst literature suggests emotional mirroring may be detrimental to young people, this study did not offer clear support either way, hence it would appear once again the situation may be more complex than first assumed and further research may help unravel this.

Developing protective factors

Young people in this study showed they valued their self-sufficiency. This finding is echoed in Thomas and colleagues' (2003) research indicating young people viewed themselves as better prepared for living away from home as a result of the skills they developed looking after themselves. Few other researchers have attended to this aspect. The young people's positive view of self-sufficiency matches Western values about the importance of autonomy. Moreover, self-sufficiency signifies achievement of the key developmental task of adolescence, gaining independence. Hence the positive experience of self-sufficiency appears to be supported at a societal level and should be considered within context. Moreover, it provides an important insight into what young people may value about their experiences of living with parental mental health difficulties.

The finding that young people adopt different adaptive coping strategies to manage difficult feelings is significant. The use of behavioural strategies was prominent in their experiences and is in line with literature underlining young people's use of distraction with hobbies and activities to cope with parental mental health difficulties (Garley *et al.*, 1997; Fudge & Mason, 2004). This indicates young people can recognise when to absorb themselves in activity to avoid entering cycles of escalating negative feelings, demonstrating their self-awareness and adaptive coping.

Furthermore, cognitive coping strategies seemed important in how the young people experienced their parent's difficulties. Cognitive defusion and acceptance appeared to underlie these strategies, fitting with acceptance and commitment therapy theory about what helps people manage difficulties (Hayes, Strosahl & Wilson, 2003). It is recognised that the

ability to reflect upon events and the self, as demonstrated by the young people in this study, is a potentially important protective factor (Place *et al.*, 2002), yet there is currently limited literature on the cognitive coping strategies young people use in the context of parental mental health difficulties. By recognising these cognitive strategies this study has broadened understanding about the resources young people draw on to cope with their situations, and, in doing so, has highlighted an important area of further research.

The role of developmental stage in experiences of parental mental health difficulties

The importance of the developmental stage of ‘adolescence’ in how the young people experienced their parent’s difficulties was apparent in the findings. The tension between independency and dependency was particularly evident in how they perceived their relationships in the family. With many taking on caring roles and valuing their self-sufficiency, they tended to construe moves towards independence and maturity positively, in line with Western discourses about the valuable nature of individuation (Hofstede, 2001). However, they also articulated a desire for continuity with boundaries and support from their parent. This fits with research indicating that, whilst adolescence requires a changing relationship with parents and a move towards autonomy, ongoing connectedness remains important (Coleman & Hendry, 1999). Whilst some valued their self-sufficiency and minimised the need for parental support, they simultaneously found the occasions when their parent was unavailable upsetting. A further indication of tension between independency and dependency was the young people’s reports of frustration at the restrictions placed on them because of their parent’s difficulties; this was mainly due to being prevented from seeing peers or pursuing personal interests. For one young person the implications of her future responsibility was pertinent as she discussed her desire to move away with the knowledge she may need to continue to support her family. This highlights some of the possible dilemmas faced by young people during adolescence in the context of parental mental health difficulties.

Given the central role of peers during this developmental stage it is interesting to consider that some young people chose not to talk to their friends about their parent’s difficulties. Anticipated stigma seemed implicated in this and hence the decision not to talk may not be specific to this developmental stage. It is hypothesised that because peer group affiliation is important during adolescence, young people may seek to avoid exposing their differences to

peers (Cleaver *et al.*, 1999). Moreover, some suggest that parental mental health difficulties may leave some young people feeling painfully different to their peers leading to feelings of shame and embarrassment (Lancaster, 1999). Whilst some acknowledged embarrassment in relation to their parent's difficulties, others spoke of their friends' acceptance and support. Thus the role of peers in relation to parental mental health difficulties appeared to vary amongst young people, demonstrating that the developmentally important experience of sharing with peers can be hindered by the stigma of parental difficulties. Hence this is an area young people may benefit from support with.

The impact of cultural contexts in experiences of parental mental health difficulties

The cultural context is a further factor worth considering, especially as there are only a few UK studies looking at young people's experiences of parental mental health difficulties. Given the link between poverty, social inequality and mental health (see e.g. Murali & Oyebode, 2004), it is important to acknowledge the possible influence of the high level of deprivation in the area where participants were recruited. As is common in areas of socio-economic disadvantage, many experienced family breakdown and lived in relatively poor conditions. For one young person the impact of this was clear as they directly linked their parent's difficulty to the poor housing and deprived environment. Likewise, it is interesting to note that many of the young people sought external factors as explanations for their parent's difficulties possibly reflecting the many stressors experienced in this context. The significance of poverty and parental divorce on young people's experiences is also emphasised in Riebschleger's (2004) research, finding that such factors were perceived as more powerful stressors than parental mental health problems.

The young people's ethnic diversity is also helpful to consider, as their varied cultural backgrounds may influence their expectations and experiences of family life and parental mental health difficulties. The stigma and marginalisation experienced by ethnic minority groups in the UK is well documented. People from ethnic minorities with mental health difficulties often face double exclusion, recognition of which has led to emphasis on tackling race inequality in mental health services (Social Exclusion Unit, 2004). This again indicates how important it is to understand contextual factors when working with families, as experiences of exclusion may be explanatory factors. Moreover, Ng's (1997) review of stigma in relation to mental health problems in non-western cultures suggests that culture

can influence how such problems are conceptualised, perceived and experienced. In Asian culture, for example, mental health difficulties are often less accepted (Ng, 1997) and more likely to be hidden due to stigma (Wahl, 1999), possibly effecting the extent to which they are acknowledged. In collectivist cultures emphasis is often placed on close family bonds, such that everyone is responsible for and contributes to family welfare (Jambunathan & Counselman, 2002). It is therefore possible that for some caring for their family in the context of parental mental health difficulties may not be dissimilar to the caring roles they would naturally assume. The role of cultural family values and expectations will be useful to consider when judging the transferability of findings. However, it is important to be mindful that the role of culture is complex and multi-dimensional, with ethnicity, socioeconomic status and family configuration just a few of the many aspects influencing a person's cultural context (Falicov, 1995).

Implications for practice

Some potentially key implications for practice emerged from the findings. Firstly, as awareness of parental mental health problems can cause difficult feelings for some young people, supporting them adequately to make sense of their parent's difficulties is important. Parents can play a crucial role in their children's sense making and hence services should seek to help them to support their children with this complex task. Uncertainty and confusion are likely to be experienced by young people as they often gain information experientially rather than formally, thus giving limited opportunity to check out their sense making. Families and services could take an active role in providing space for young people to talk through their sense making. Cooklin (2006) advocates the benefits of *Kidstime* workshops where families are given psychoeducation about mental health difficulties. However, this study indicates it is important to work from the position of young people's sense making, as the explanations they reach are likely to be diverse and include external factors. Remaining aware that professional explanations may not be helpful is vital, as they may not match young people's experiences of their parent's difficulties. It may be preferable to encourage families to develop their own shared meaning for mental health difficulties, as advocated by some clinicians (Daniel & Wren, 2005; Fredman & Fuggle, 2000; Place *et al.*, 2002). Clinical psychologists' knowledge of child development and experience of working in both adult mental health and child and family settings could be invaluable, as they have the skills to develop collaborative understandings with families. Paying attention to the context and the potential role of poverty may help to ensure explanations match family experiences, hence clinical psychologists' ability to formulate difficulties in context could prove beneficial.

Secondly, it is important to be mindful that developing a trusting relationship with young people might be necessary before they feel able to talk about their parent's difficulties. Therefore, supporting adults, who have established ongoing supportive relationships with young people, to talk about parental difficulties may prove useful. Moreover, young people may find talking with adults who are already part of their lives less stigmatising than speaking to professionals. Services aiming to support young people in this context should allow time for professionals to build relationships with them, as being available over time may make it easier to develop trust. Working with families together may be advantageous as

family loyalty is thought to hinder conversations (Falkov, 1998), thus young people observing their parents trusting professionals may be encouraged to talk. It may be useful to explore beliefs about talking to professionals and the consequences for their family situation. Making the barriers to talking explicit may allow them to be worked with. Taking into account that not all want to talk, support should be matched to each young person's needs. Consideration of using creative and non-verbal therapies such as art, play, drama or dance and movement therapy may be helpful, allowing a medium for young people to express their feelings without the pressure of talking. To the same end talking therapies could incorporate creative aspects such as drawing or play. Supporting parents in giving their children overt permission to talk is important, as reluctance to talk may reflect a family pattern of choosing not to talk. Furthermore encouraging families to have ongoing conversations about parental mental health difficulties may foster young people's communication and help them overcome any uncertainty.

Thirdly, services and professionals have a key role in increasing mental health awareness and acceptance given the underlying theme of stigma surrounding parental mental health difficulties. This work may fit well with the roles of professionals working within Tier 2 CAMHS, as they are likely to have links with the community across a variety of settings. Moreover, as advocated by Scott (1994), the media could be used to good effect to access a wider audience, like psychologist Dr. Tanya Byron does.

Fourthly, it may be helpful to approach the complex nature of relationships between parents with mental health difficulties and their children from a positive stance, perhaps using the frame of reciprocity as a starting point. Providing this context may free young people to view the whole of their experience and facilitate talking about the difficult aspects and any risk issues. In addition inviting stories of active response from them will build on narratives of adaptation and resourcefulness (White, 2006a), revealing their strengths and perhaps making them more willing to talk. This could help direct work towards strengthening existing skills and resources to enhance coping.

Lastly, encouraging consistent sources of support for young people through family, friends and the community is advantageous. Voluntary services, such as the Family Welfare Association and Young Carers Projects, can play a vital role having the potential to offer consistent long-term support. During this research I became increasingly aware of the

pressure these services are under due to a scarcity of resources and short-term funding agreements. Hence, I feel an important implication of the findings is to give greater priority to supporting and maintaining voluntary services' community projects. Equally the NHS should give prominence to maintaining ongoing support for families in the context of parental mental health difficulties.

Methodological considerations

The methodological approach fitted with the research aims, allowing for a set of rich, complex and rigorous findings about the young people's experiences. As IPA is an idiographic approach which does not seek to find definitive and positivist answers, it is not possible to generalise the findings to all young people living with parental mental health difficulties. Instead IPA aims to contribute to a gradually developing knowledge base, resonating with professional and personal experiences and shedding light on the broader context (Smith & Osborn, 2008). Thus, whilst others may have similar experiences, it is necessary to acknowledge that the findings provide an in-depth insight into the salient themes of the participants' experiences in this specific study (Smith & Osborn, 2003) and the findings' transferability must be considered within context. The findings did resonate with existing literature and professionals' experiences, increasing their claim to credibility. However, there are implicit limitations arising from the interpretative nature of the study. Although I have strived to ensure trustworthiness and transparency throughout all stages of analysis and interpretation, it is acknowledged that what are presented are my interpretations, and others may have found something else salient.

One possibility that occurred to me when analysing the transcripts was the potential for multiple interviews with young people to yield richer accounts. Given the difficulty some expressed in talking about their parent's difficulties, I wondered whether taking a longitudinal approach would be advantageous; perhaps enabling them to share more. However, such an approach would need to be balanced with the demands on young people in terms of time and effort.

As with any research there is a potential selection bias amongst those choosing to participate. This is perhaps less problematic because of the idiographic nature of IPA as generalisations are not intended, yet it needs to be borne in mind when considering the transferability of

findings. It is important to be aware that the experiences of those choosing not to participate might differ considerably from those taking part. Moreover, it is likely that the professionals recruiting young people to participate may have been selective in who they asked, perhaps more inclined to ask those who they felt may be interested or willing. Furthermore the research only captured people known to either voluntary or child and adolescent mental health services, again there may be differences between these young people and those not accessing such services. Adult services for example might provide access to other young people and within the community there are those whose parents and families do not receive any support from services. Both these populations might have qualitatively different experiences of living with parental mental health problems to the young people in this research, hence recruitment strategy needs consideration when contemplating the findings' transferability.

A further factor that might have influenced who chose to participate and what was shared in interviews was the gift voucher given to participants. The decision to give vouchers was informed by my wish to acknowledge the young people's valuable contribution, in addition to attracting them to participate. I was particularly concerned with making participation appealing because of the difficulties highlighted by other researchers in engaging this population (Aldridge & Becker, 2003; Handley *et al.*, 2001; Stallard *et al.*, 2004). The voucher could have influenced what was shared in several ways, for example increasing social desirability. This could have perhaps made the young people more guarded about revealing their personal experiences due to fear of judgement, or it may have made them share more to justify receiving the voucher, or say what they thought was expected.

Recruitment difficulties encountered by other researchers were congruent with my experience. I found barriers such as the way mental health difficulties were conceptualised by young people and others wishing to protect them from talking in case they found it upsetting, in addition to some young people's reluctance to talk. Understanding that many young people do not conceptualise their parent's difficulties as mental health difficulties is crucial when carrying out research in this area. This research explicitly stated it was about parental mental health difficulties and, hence, required the young people to accept their parent's difficulties could be conceptualised in this way. The problems with this were evident when one young person recruited initially misunderstood what the study was about and, then, did not see it as applicable despite fitting the inclusion criteria. This raises an

interesting dilemma when carrying out research in this area between transparency in research aims and making it meaningful to potential participants. It highlights the importance of language and the need to be creative to balance these issues. Moreover it warns of the potential disadvantages of using professional conceptualisations and not matching understanding to the target population. Overall the recruitment difficulties illustrated how far there is to go in improving the acceptance of mental health problems as a common part of life which can be discussed openly.

Carrying out IPA with adolescents provided me with the challenge of how to gain rich and detailed accounts from a population traditionally considered less articulate (Nelson & Quintana, 2005). Guidelines for conducting qualitative interviews with young people indicated including specific prompts and direct questions aid the interview process (Irwin & Johnson, 2005; Nelson & Quintana, 2005). With this in mind I sought to balance these to enable the young people to feel at ease and express their experiences whilst giving them flexibility to tell their own story. In this regard I am aware the interviews differed somewhat to IPA interviews with adults where dialogue is likely to be more free-flowing and open ended. However, given the difference in context, the adaptations seemed appropriate, appearing to facilitate young people's expression of their experiences.

A further methodological issue arising related to the feedback I received from the young people. Whilst there are conflicting views on the benefits of sharing analysis with participants in IPA research, I chose to invite feedback to include them in the research process and give them the chance to offer alternative views, hence developing a richer account. Two responded saying they had found receiving the interview transcript and summary of themes upsetting. On reflection I wonder whether writing to them was the best way to achieve my aims. Perhaps using follow-up interviews to talk over the themes and gain their feedback would have been better; this may have been less threatening and could have enabled me to clarify any issues arising. I also wonder whether it may have been preferable not to consult with the young people for feedback, as it is argued to be inappropriate if participants are unable to relate to the analysis (Yardley, 2008). This was possibly the case for this study given the interpretive element in the analysis and attention to contradictions and suppressed meaning within the young people's experiences. Whilst I endeavoured to ensure the summary of themes was accessible and grounded in the young people's language, it seems it did not match their needs. In retrospect, giving them each their

transcript may have been inadvisable. Whilst I intended it to enhance transparency of the analysis and aid their appraisal of the themes reached, in practice the disjointed and fragmented nature of talk may have been difficult for them to recognise given they are likely to experience their talk as more fluid and coherent.

Suggestions for further research

Qualitative research exploring the experiences of young people whose parents have mental health difficulties is still in its infancy, thus further qualitative research could build on the current findings. Particular areas of focus could include exploring young people's experiences at different developmental stages, from different social contexts and whose parents have different difficulties or are at different stages in the course of them. As the current study focused on 13-15 year olds, future research could include younger children and older adolescents to consider how developmental stages may influence the experience of parental mental health difficulties. Consideration of the possible interaction between young people's gender and their experience of parental problems could also be a future research focus. Exploring the influence of socially constructed masculinities and femininities on adaptation could provide further understanding about the role of gender and how this may affect the support young people need. In addition different strategies of recruitment could be used to target different populations of young people. Including those from different social contexts could expand understanding as to how this interacts with experiences of parental mental health difficulties. Moreover, research could widen the scope of parental difficulties beyond depression and anxiety. Whilst this study used a broad definition for parental mental health problems there was a noticeable absence of difficulties traditionally considered severe and enduring, such as, psychosis or bipolar disorder. It is possible that young people whose parents experience difficulties such as psychosis or bipolar disorder may experience their parents as less available. These difficulties can often involve both physical and emotional parental 'absences' due to periods of hospitalisation or preoccupation with thoughts, perceptual experiences or emotions. Given the importance of consistency of support highlighted in this research, their experiences may be very different from the young people in this study and warrant exploration. A longitudinal approach to research could be particularly beneficial for considering how young people experience their parent's difficulties over time, with interviews perhaps when parents first develop difficulties and at regular follow-ups.

One vital aspect to future research should be the active inclusion of young people whose fathers have mental health difficulties, as living with paternal mental health difficulties may result in a qualitatively different experience to maternal difficulties. This study did not specify which parent should have difficulties, but no young people whose fathers had difficulties participated. The lack of attention to paternal mental health has been highlighted in the literature (Connell & Goodman, 2002; Hammen, 2003; Parrott *et al.*, 2008; Seifer, 2003) and suggests special emphasis is needed in this area, as a general approach may not be sufficient.

Research on young people living with parental mental health difficulties could be progressed to consider how their experiences fit with other family members' perspectives. Taking a systemic perspective could help elucidate the relational processes within these families, thus broadening knowledge about communication, parental relationships and family resources in this context. Whilst this is a complex area of research to undertake, some researchers are attempting this (Colmer, 2005).

Recognising the important role of attachment in child development, research is needed focusing on how attachment relationships foster resilience in families with parental mental health problems. Attachment literature highlights the importance of continuity, availability and responsivity in relationships; hence reparation of relationship ruptures is a central aspect of attachment (Hughes, 2007). With this study highlighting fluctuations in parent availability and responsivity, researching how ruptures are repaired in the context of parental mental health difficulties will help further understanding.

An important area of research will be evaluating the effectiveness of services working with parental mental health difficulties. The research focus will need to match the aims of the service, whether it is to support children's sense making, provide them with mental health education, increase family protective factors, such as participation in community activities or help children develop adaptive coping strategies.

With consistency of support identified as valuable in this study, research at a community level may prove advantageous, as community projects may have the capacity to provide a sense of belonging. Action-orientated research exploring the needs and resources of

communities in relation to parental mental health difficulties would be useful and may also enhance the profile of such important initiatives.

Moreover, I feel further emphasis on the resources and adaptive coping of young people whose parents have mental health problems is necessary. Exploring their perceptions of what they feel has contributed to their development and been beneficial will be helpful. This may give further insight into the resilience processes that occur and help direct services as to how to enhance such processes.

This study indicates that particular consideration should be given to young people's cognitive strategies, as these potentially significant protective factors have received limited attention. Investigation into how parental mental health difficulties influence the development of such strategies and their effect on young people's well-being are important areas to pursue. Likewise the link between strategies found in this study, such as acceptance and cognitive defusion, with the theory underlining acceptance and commitment therapy (Hayes *et al.*, 2003) may be beneficial to examine. It could give further insight into the processes that help young people manage their experiences. Building knowledge in this area seems promising as it may directly inform clinical practice, improving support offered to families.

Overall I feel there are many areas worthy of further exploration in parental mental health of which I have outlined just a few. With the increasing acknowledgement of the limited research and the need to adopt a strengths based stance focusing on family resilience (Parrott *et al.*, 2008), it is an exciting time to undertake research with many promising avenues to explore.

Study reflections

The most rewarding aspect of the research was the privilege of the young people sharing their personal experiences with me. I had great admiration for the way they accepted their parent's difficulties and endeavoured to support them and was encouraged to hear of the strengths and resources they gained from their experiences. However, I also experienced empathy and sorrow for their confusion around their parent's problems and the difficulties coming to terms with their parent's distress, wondering how I would have made sense of such experiences in my childhood. The opportunity to seek supervision helped me manage the emotional impact of interviews and consider the potential influence on my analysis.

The overall process has given me greater understanding of the inevitable challenges faced when carrying out research. My experience has taught me the importance of support and supervision in keeping momentum going and how good relationships with those recruiting are key to ensuring research proceeds. Moreover, I feel I have gained valuable skills and experience that will be helpful in future research and clinical work. In particular carrying out the interviews focused my attention on my interview style, increasing my awareness of how to use open-ended questions effectively to build an understanding of someone's experience. The process of analysis highlighted for me the importance of attending to the detail of language to gain a deeper understanding of people's experience, and how immersion in data benefits this process. However, I also found that such close contact with the data had some disadvantages, as my desire to do justice to the young people's experience made it hard to let go of themes and feel confident I had captured the main essence of their experiences. A further aspect I found difficult was the process of requesting feedback from the young people. I felt hesitant doing this, fearing that reading the transcripts and themes might upset them. My concern was confirmed when two participants replied saying they were upset by what they read. I found this particularly difficult as whilst interviewing I had felt protective towards them because of their age and the sensitivity of the topic and was keen that their participation was a positive experience. This experience will guide if, and how, I will approach requesting feedback in the future.

Perhaps, most importantly, this study has directly shown me the value of research in helping inform clinical practice. The clinical implications outlined earlier will guide me when working with parental mental health difficulties in future and encourage me to maximise

dissemination of this research. In particular this study has raised my awareness of the complex nature of relationships in the presence of parental mental health problems and the strong bonds potentially generated. It has also reinforced my preference for a strengths-based approach when working with families, underlining the importance of working in context.

Conclusions

This study has added to knowledge about young people's experiences of living with parental mental health problems. The use of IPA has allowed a rich account of their experiences to be developed, consistent with existing literature, and importantly has given further detail and nuance to what is already known. The key findings that young people become aware of their parents difficulties through observation, experience uncertainty and may struggle to make sense because of difficulty talking about parental mental health problems, indicate the need to support young people with this process. As young people may develop external explanations for their observation it is important that explanations given are contextual and match family understandings. The complexity of relationships between parents and young people has also come to light, indicating they can have strong bonds, engendering reciprocal caring within the family. Significantly the young people experienced their parents as loving and caring, with some simultaneously reconciling the fragility of this and the potential for their parent to be unavailable at times. Moreover, the importance of consistent support, the positive experience of feeling self-sufficient and the adaptive coping strategies that young people develop, indicate their valuable strengths and protective factors. This can help guide clinical practice and focus attention on how young people and families experiencing parental mental health difficulties can be best supported. Emphasising the development of strengths and resources and attending to issues of risk whilst appreciating the close, caring and complex relationships existing between young people and parents in the context of mental health problems may prove helpful.

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Appendix 1- Service Information

Parental Mental Health Support

(A Family Welfare Association's Building Bridges project)

Based in Hackney, the project supports families affected by enduring parental mental health problems and other complex needs, aiming to bridge the gap between adult and children services. The Parental Mental Health Support project is run by one support co-ordinator on a full-time basis and supports approximately 33 families, providing practical and emotional help.

Hackney Young Carers

The Young Carers Project supports young carers in Hackney under 18 who look after someone who is seriously ill, disabled or elderly; offering a variety of groups and trips they provide respite to young carers. The Young Carers Project supports approximately 150 young carers and is run by one full time member of staff and one part time member of staff, in addition to volunteers.

Appendix 2- Ethical approval documents

SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL

Student Investigator: Cassie Bromley

Title of project: An interpretative phenomenological analysis of young people's experiences of living with a parent with mental health difficulties.

Supervisor: Pieter Nel

Registration Protocol Number: PSY/06/07/CB

The approval for the above research project was granted on 27 June 2007 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.

Signed:



Date: 27 June 2007

Dr. Lia Kvavilashvili

Chair

Psychology Ethics Committee

STATEMENT OF THE SUPERVISOR:

From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.

Signed (supervisor):

Date:

Appendix 2- Ethical approval documents

Hounslow & Hillingdon Local Research Ethics Committee

50 Eastbourne Terrace
2nd Floor A Block
London
W2 6LG

Telephone: 020 7725 5672

Facsimile: 020 7725 5317

01 October 2007

Miss Cassie Bromley
Trainee Clinical Psychologist
University of Hertfordshire
University of Hertfordshire
College Lane
Hatfield, Hertfordshire
AL10 9AB

Dear Miss Bromley

Full title of study: **An interpretative phenomenological analysis of the experiences of young people living with a parent with mental health difficulties**

REC reference number: **07/H0705/61**

Thank you for your letter of 27 September 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	1	18 August 2007
Investigator CV		28 June 2007
Protocol	1	
Covering Letter		13 July 2007
Covering Letter		27 September 2007
Peer Review		05 April 2007
Compensation Arrangements		01 August 2006
Interview Schedules/Topic Guides	1	
Participant Information Sheet: Information Sheet for Parents/Carers	2	27 September 2007
Participant Information Sheet: Information for Young People	2	27 September 2007
Participant Consent Form: for parents/carers	1	
Participant Consent Form: for young people	1	
Response to Request for Further Information		27 September 2007
Supervisor CV		
References	1	
Confidentiality agreement	1	
Letter of Introduction	1	27 September 2007

R&D approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain research governance approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Guidance on applying for R&D approval is available from <http://www.rdforum.nhs.uk/rdform.htm>.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

<https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx>

We value your views and comments and will use them to inform the operational process and further improve our service.

07/H0705/61

Please quote this number on all correspondence

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

Yours sincerely

Jan Downer
Chair

Email: irene.gordon@nationalres.org.uk

Enclosures: Standard approval conditions SL-AC2

Copy to: Dr Nick Wood, University of Hertfordshire
Ms Cindy Hall, R&D Manager, City & Hackney Teaching PCT

Hounslow & Hillingdon Local Research Ethics Committee

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	07/H0705/61	Issue number:	0	Date of issue:	01 October 2007
Chief Investigator:	Miss Cassie Bromley				
Full title of study:	An interpretative phenomenological analysis of the experiences of young people living with a parent with mental health difficulties				
<i>This study was given a favourable ethical opinion by Hounslow & Hillingdon Local Research Ethics Committee on 27 September 2007. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.</i>					
Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes ⁽¹⁾
Ms Lizette Nolte	Consultant Clinical Psychologist	East London and City Mental Health NHS Trust	Hounslow & Hillingdon Local Research Ethics Committee	01/10/2007	
Approved by the Chair on behalf of the REC:					
..... (Signature of Chair/Co-ordinator) (delete as applicable)					
..... (Name)					

(1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*



INFORMATION SHEET FOR YOUNG PEOPLE

Title of project: Young people's experiences of living with a parent with mental health difficulties.

Introduction

We are asking young people aged 13 to 18 to take part in a research project to find out about the experiences of young people living with a parent with mental health difficulties. Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you. So please consider this information sheet carefully. Talk about it with your family, friends, or health worker if you want to.

The researchers

The study is being carried out by Cassie Bromley, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology. The study is supervised by Dr Pieter Nel, Clinical Lecturer and Consultant Clinical Psychologist, and Ms Lizette Nolte, Consultant Clinical Psychologist.

Why are we doing this research?

We want to learn from your experiences, to better understand the needs of young people living with parental mental health difficulties, what you want from services and how services can best support you. Parental mental health difficulties can have a significant effect on young people's lives, both positively and negatively; we feel increased understanding will help us make services better at meeting young people's needs and help families who want support.

What is involved?

If you decide to take part, you will be invited to take part in an in-depth interview lasting approximately one hour about your experience of living with a parent with mental health problems. Areas you will be asked about include how you understand your parent's difficulties, what impact it has on your life, what helps you and what positive aspects there are living with parental mental health problems.

Who is taking part?

Young people aged 13-18 who are living with a parent with mental health difficulties are being invited to take part. Your parent must either have a current mental health diagnosis or be in contact with a health professional about their difficulties (e.g. GP, Mental Health Services). This study is only for people who speak English, as interpreters will not be available. This study aims to recruit between 6-8 young people.

Do I have to take part?

No. It is up to you. If you do take part, you will be asked to sign a form giving your consent. You will be given a copy of this information sheet and your signed form to keep. You are free to stop taking part **at any time** during the research without giving a reason. If you decide not to take part or to stop, this will not affect the care you or your family receive

What do I have to do?

If after reading this information sheet you would like to take part in the research, you will be given this sheet to keep and need to sign two consent forms. You will keep one copy of the signed consent form and the researchers will keep another copy. (If you are under 16, your parent will also need to complete two consent forms for you to take part in the study and they will also be given an information sheet to keep.) You will be asked to complete a personal information sheet and take part in an in-depth interview, lasting approximately one hour. The interview will take place in a private and quiet environment, at a location convenient to you; your home, the University of Hertfordshire or another suitable location. The interview will be recorded and as detailed above involve answering questions about your experience of living with a parent with mental health difficulties.

Will taking part be confidential?

Yes. If you decide to take part, we will keep your information in confidence. All information (i.e. your consent form, personal information sheet, interview audio-tape and transcript) will be kept at a secure location which will only be accessible by the researchers. Your parents will not have access to the interview. The interview transcript (a write up of what is said in the interview) will not contain your name, instead a number will be used, and the same number will be written on your personal information sheet. There is a possibility that a non-researcher will be used to write up the interviews, if so they will be known to the University Of Hertfordshire and sign a confidentiality agreement. The overall findings of the project may be published in a research paper, which may include direct quotes from interviews; however no individuals will be identifiable.

The only time information from the interview would be shared with other professionals, would be in exceptional circumstances if you revealed information about yourself that may indicate a risk of harm to yourself or others.

What are the benefits of taking part?

Many people find the opportunity to talk about and make sense of their experiences positive and helpful.

We cannot promise the study will help you, but the information will help develop understanding of the experiences of young people who live with parental mental health difficulties, so families can be offered the best support in the future. To keep you informed about this, if you take part will be asked if you would like a written summary of the results once the research has been completed.

If you have travelled to the location of the interview, travel expenses will be reimbursed up to the value of £10 on the production of travel receipts. You will be offered a £10 gift voucher, as a small thank you for your time.

What if I have questions or concerns?

If you have any further questions about the research, please feel free to contact me via email, telephone or post, details of which are below. In the unlikely event that taking part in this research has upset you in some way, please contact me as I will be able to tell you where you can access further help.

Who has reviewed this study?

This study has been approved by the Psychology Ethics Committee at the University of Hertfordshire, protocol number PSY/06/07/CB.

Thank you for taking time to read this.

Contact details of the researcher:

Cassie Bromley

Email address: c.bromley@herts.ac.uk

Telephone number: 01707 286 322

Postal address: Doctor of Clinical Psychology Training Course
University of Hertfordshire, Hatfield, Herts., AL10 9AB

INFORMATION SHEET FOR YOUNG PEOPLE

Title of project: Young people's experiences of living with a parent with mental health difficulties.

Introduction

We are asking young people aged 13 to 18 to take part in a research project to find out about the experiences of young people living with a parent with mental health difficulties. Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you. So please consider this information sheet carefully. Talk about it with your family, friends, or health worker if you want to.

The researchers

The study is being carried out by Cassie Bromley, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology. The study is supervised by Dr Pieter Nel, Clinical Lecturer and Consultant Clinical Psychologist, and Ms Lizette Nolte, Consultant Clinical Psychologist.

Why are we doing this research?

We want to learn from your experiences, to better understand the needs of young people living with parental mental health difficulties, what you want from services and how services can best support you. Parental mental health difficulties can have a significant effect on young people's lives, both positively and negatively; we feel increased understanding will help us make services better at meeting young people's needs and help families who want support.

What is involved?

If you decide to take part, you will be invited to take part in an in-depth interview lasting approximately one hour about your experience of living with a parent with mental health problems. Areas you will be asked about include how you understand your parent's difficulties, what impact it has on your life, what helps you and what positive aspects there are living with parental mental health problems.

Who is taking part?

Young people aged 13-18 who are living with a parent with mental health difficulties are being invited to take part. Your parent must either have a current mental health diagnosis or be in contact with a health professional about their difficulties (e.g. GP, Mental Health Services). This study is only for people who speak English, as interpreters will not be available. This study aims to recruit between 6-8 young people.

Do I have to take part?

No. It is up to you. If you do take part, you will be asked to sign a form giving your consent. You will be given a copy of this information sheet and your signed form to keep. You are free to stop taking part **at any time** during the research without giving a reason. If you decide not to take part or to stop, this will not affect the care you or your family receive.

What do I have to do?

If after reading this information sheet you would like to take part in the research, you will be given this sheet to keep and need to sign two consent forms. You will keep one copy of the signed consent form and the researchers will keep another copy. (If you are under 16, your parent will also need to complete two consent forms for you to take part in the study and they will also be given an information sheet to keep.) You will be asked to complete a personal information sheet and take part in an in-depth interview, lasting approximately one hour. The interview will take place in a private and quiet environment, at a location convenient to you; your home, the University of Hertfordshire or another suitable location. The interview will be recorded and involve answering questions about your experience of living with a parent with mental health difficulties.

If you have travelled to the location of the interview, travel expenses will be reimbursed up to the value of £10 on the production of travel receipts. You will be offered a £10 gift voucher, as a small thank you for your time.

Will taking part be confidential?

Yes. If you decide to take part, we will keep your information in confidence. All information (i.e. your consent form, personal information sheet, interview audio-tape and transcript) will be kept at a secure location which will only be accessible by the researchers. Your parents will not have access to the interview. The interview transcript (a write up of what is said in the interview) will not contain your name, instead a number will be used, and the same number will be written on your personal information sheet. There is a possibility that a non-researcher will be used to write up the interviews, if so they will be known to the University Of Hertfordshire and sign a confidentiality agreement. The overall findings of the project may be published in a research paper, which may include direct quotes from interviews; however no individuals will be identifiable.

The only time information from the interview would be shared with other professionals, would be in exceptional circumstances if you revealed information about yourself that may indicate a risk of harm to yourself or others.

What are the benefits of taking part?

Many people find the opportunity to talk about and make sense of their experiences positive and helpful.

We cannot promise the study will help you, but the information will help develop understanding of the experiences of young people who live with parental mental health difficulties, so families can be offered the best support in the future. To keep you informed about this, if you take part will be asked if you would like a written summary of the results once the research has been completed.

What if I have questions or concerns?

If you have any further questions about the research, please feel free to contact me via email, telephone or post, details of which are below. In the unlikely event that taking part in this research has upset you in some way, please contact me as I will be able to tell you where you can access further help.

Who has reviewed this study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the Hounslow and Hillingdon NHS Research Ethics Committee.

Thank you for taking time to read this.

Contact details of the researcher:

Cassie Bromley

Email address: c.bromley@herts.ac.uk

Telephone number: 01707 286 322

Postal address: Doctor of Clinical Psychology Training Course
University of Hertfordshire, Hatfield, Herts., AL10 9AB

Appendix 4- Information Sheet for Parents/ Carers (Voluntary Organisations version)



INFORMATION SHEET FOR PARENTS /CARERS

Title of project: An interpretative phenomenological analysis of young people's experiences of living with a parent with mental health difficulties.

Introduction

Young people between the ages of 13 and 18 are being invited to take part in a research study to explore the experiences of young people living with a parent with mental health difficulties. Before you decide whether you would like to give consent for your son/daughter to take part, please take the time to read the following information which I have written to help you understand why the research is being carried out and what it will involve.

The researchers

The study is being carried out by Cassie Bromley, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology. The study is supervised by Dr Pieter Nel, Clinical Lecturer and Consultant Clinical Psychologist, and Ms Lizette Nolte, Consultant Clinical Psychologist.

What is the purpose of the study?

This research is looking at young peoples' experience of living with parental mental health difficulties. We know that parents are often concerned about the impact of their difficulties on their children and want their families to receive the best support available. We would like to learn from young people's experiences in order to better understand young people's needs, what they want from services and how services can best support them. Parental mental health difficulties can have a significant effect on children's lives, both positively and negatively; we feel increased psychological understanding will help tailor services to better meet young people's needs and help families who want support.

What is involved?

If you decide your son/daughter can take part, they will be required to take part in an in-depth interview lasting approximately one hour about their experience of living with a parent with mental health problems. Areas they will be asked about include how they understand their parent's difficulties, what impact it has on their life, what helps them and what are the positive aspects of living with a parent with mental health difficulties.

Who is taking part?

This study will include young people aged 13-18 years of age who are living with a parent with mental health difficulties. One or both parents will either have a current mental health diagnosis or be in contact with a health professional about their difficulties (e.g. GP, Mental Health Services). The young people taking part will be English speaking, as interpreters will not be available. This study aims to recruit between 6-8 young people.

Do I have to take part?

No. If you do not want your child to take part, or you change your mind *at any time* during participation in this study, you can withdraw and do not need to give a reason. Participation is entirely voluntary and you can withdraw at any time.

What do I have to do?

If after reading this information sheet you agree to your son/daughter taking part in the research, you will be given this sheet to keep and need to sign two consent forms. You will keep one copy of the signed consent form and the researchers will keep another copy. Your son and daughter will also be provided with an information sheet and asked to sign consent forms if they wish to take part in the study. Your son/daughter will be contacted to arrange a time to meet for an in-depth interview. The interview will last for approximately one hour and will take place in a private and quiet environment, at a location convenient to them; their home, the University of Hertfordshire or another suitable location. The interview will be recorded and as detailed above involve answering questions about their experience of living with a parent with mental health difficulties.

If your son/daughter has travelled to the location of the interview, travel expenses will be reimbursed up to the value of £10 on the production of travel receipts. They will also be offered a £10 gift voucher, as a small thank you for their time.

Will taking part be confidential?

Yes. If your son/daughter decides to take part, all information (i.e. consent forms, personal information sheet, interview audio-tape and transcript) will be kept at a secure location which will only be accessible by the researchers. This means you will not have access to the interview. The interview transcript (a write up of what is said in the interview) will not contain their name, instead a number will be used, and the same number will be written on their personal information sheet. There is a possibility that a non-researcher will be used to transcribe the interviews, if so they will be known to the University Of Hertfordshire and sign a confidentiality agreement. The overall findings of the project may be published in a research paper, which may include direct quotes from interviews; however no individuals will be identifiable.

The only time information from the interview would be shared with other professionals, would be in exceptional circumstances when a young person reveals information about themselves that may indicate a risk of harm to themselves or others.

What are the benefits of taking part?

Many people find the opportunity to talk about and make sense of their experiences positive and helpful.

More generally, it is hoped that this research will help develop psychological understanding of the experiences of young people who live with parental mental health difficulties, so families can be offered the best support. To keep those who participate informed about this, participants will be asked if they would like a written summary of the results once the research has been completed.

What if I have questions or concerns?

If you have any further questions about the research, please feel free to contact me via email, telephone or post, details of which are below. In the unlikely event that participating in this research has caused a young person distress in some way, please do not hesitate to contact me, as I will be able to advise you on where they may be able to access further help.

Who has reviewed this study?

This study has been approved by the Psychology Ethics Committee at the University of Hertfordshire, protocol number PSY/06/07/CB.

Thank you for taking time to read this.

Contact details of the researcher:

Cassie Bromley

Email address: c.bromley@herts.ac.uk

Telephone number: 01707 286 322

Postal address: Doctor of Clinical Psychology Training Course,
University of Hertfordshire,
Hatfield,
Herts.,
AL10 9AB

Ref: 07/H0705/61
Researcher: Cassie Bromley
Version 2 (27.09.07)

INFORMATION SHEET FOR PARENTS /CARERS

Title of project: An interpretative phenomenological analysis of young people's experiences of living with a parent with mental health difficulties.

Introduction

Young people between the ages of 13 and 18 are being invited to take part in a research study to explore the experiences of young people living with a parent with mental health difficulties. Before you decide whether you would like to give consent for your son/daughter to take part, please take the time to read the following information which I have written to help you understand why the research is being carried out and what it will involve.

The researchers

The study is being carried out by Cassie Bromley, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology. The study is supervised by Dr Pieter Nel, Clinical Lecturer and Consultant Clinical Psychologist, and Ms Lizette Nolte, Consultant Clinical Psychologist.

What is the purpose of the study?

This research is looking at young peoples' experience of living with parental mental health difficulties. We know that parents are often concerned about the impact of their difficulties on their children and want their families to receive the best support available. We would like to learn from young people's experiences in order to better understand young people's needs, what they want from services and how services can best support them. Parental mental health difficulties can have a significant effect on children's lives, both positively and negatively; we feel increased psychological understanding will help tailor services to better meet young people's needs and help families who want support.

What is involved?

If you decide your son/daughter can take part, they will be required to take part in an in-depth interview lasting approximately one hour about their experience of living with a parent with mental health problems. Areas they will be asked about include how they understand their parent's difficulties, what impact it has on their life, what helps them and what are the positive aspects of living with a parent with mental health difficulties.

Who is taking part?

This study will include young people aged 13-18 years of age who are living with a parent with mental health difficulties. One or both parents will either have a current mental health diagnosis or be in contact with a health professional about their difficulties (e.g. GP, Mental Health Services). The young people taking part will be English speaking, as interpreters will not be available. This study aims to recruit between 6-8 young people.

Do I have to take part?

No. If you do not want your child to take part, or you change your mind *at any time* during participation in this study, you can withdraw and do not need to give a reason. Participation is entirely voluntary and you can withdraw at any time.

What do I have to do?

If after reading this information sheet you agree to your son/daughter taking part in the research, you will be given this sheet to keep and need to sign two consent forms. You will keep one copy of the signed consent form and the researchers will keep another copy. Your son and daughter will also be provided with an information sheet and asked to sign consent forms if they wish to take part in the study. Your son/daughter will be contacted to arrange a time to meet for an in-depth interview. The interview will last for approximately one hour and will take place in a private and quiet environment, at a location convenient to them; their home, the University of Hertfordshire or another suitable location. The interview will be recorded and as detailed above involve answering questions about their experience of living with a parent with mental health difficulties.

If your son/daughter has travelled to the location of the interview, travel expenses will be reimbursed up to the value of £10 on the production of travel receipts. They will also be offered a £10 gift voucher, as a small thank you for their time.

Will taking part be confidential?

Yes. If your son/daughter decides to take part, all information (i.e. consent forms, personal information sheet, interview audio-tape and transcript) will be kept at a secure location which will only be accessible by the researchers. This means you will not have access to the interview. The interview transcript (a write up of what is said in the interview) will not contain their name, instead a number will be used, and the same number will be written on their personal information sheet. There is a possibility that a non-researcher will be used to transcribe the interviews, if so they will be known to the University Of Hertfordshire and sign a confidentiality agreement. The overall findings of the project may be published in a research paper, which may include direct quotes from interviews; however no individuals will be identifiable.

The only time information from the interview would be shared with other professionals, would be in exceptional circumstances when a young person reveals information about themselves that may indicate a risk of harm to themselves or others.

What are the benefits of taking part?

Many people find the opportunity to talk about and make sense of their experiences positive and helpful.

More generally, it is hoped that this research will help develop psychological understanding of the experiences of young people who live with parental mental health difficulties, so families can be offered the best support. To keep those who participate informed about this, participants will be asked if they would like a written summary of the results once the research has been completed.

What if I have questions or concerns?

If you have any further questions about the research, please feel free to contact me via email, telephone or post, details of which are below. In the unlikely event that participating in this research has caused a young person distress in some way, please do not hesitate to contact me, as I will be able to advise you on where they may be able to access further help.

Who has reviewed this study?

This study has been approved by the Hounslow and Hillingdon NHS Research Ethics Committee.
Thank you for taking time to read this.

Contact details of the researcher:

Cassie Bromley

Email address: c.bromley@herts.ac.uk

Telephone number: 01707 286 322

Postal address: Doctor of Clinical Psychology Training Course, University of Hertfordshire, Hatfield,
Herts., AL10 9AB

Appendix 5- Introductory letter for Young People

Hi,

My name is Cassie Bromley and I am a Clinical Psychology trainee at the University of Hertfordshire. I would like to invite you to take part in a research project. The research is about young people's experiences of living with a parent with mental health problems. Through this research I hope to learn more about what it is like for you living with a parent with mental health difficulties and what helps you cope, to make services better at meeting young people's needs and help families who want support.

Taking part in the project involves being interviewed (for approximately an hour) so I can learn about your experience.



Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you. More detailed information about the research is on the 'Information Sheet for Young people'; this includes details of how you can contact me if you have any questions. Please consider the information sheet carefully and talk about it with your family, friends or health worker if you want to.



You do not have to take part, it is up to you. If you do want to take part, you will be asked to sign a form giving your consent. You will be given a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide not to take part or to stop, this will not affect the care you or your family receive.



We cannot promise the study will help you but the information we get might help us support young people and their families when a parent has mental health problems in the future.

If you take part you will be given a **£10 gift voucher** as a thank you for your time and help.



Thanks for taking time to read this.

I hope you will consider taking part and read the 'Information sheet for young people'.

Best wishes,

Cassie Bromley

Appendix 6- Consent Form for Young People (Voluntary Organisations version)



CONSENT FORM

Title of Project: An interpretative phenomenological analysis of young people’s experiences of living with a parent with mental health difficulties.

Researcher: Cassie Bromley, Trainee Clinical Psychologist

Please tick box

- 1) I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information and if needed ask questions that were satisfactorily answered.

- 2) I understand that participation is voluntary and I am free to withdraw at any time, without giving any reason, without healthcare or legal rights being affected.

- 3) I agree to take part in the above study

- 4) I agree for the interview to be audio-recorded

.....
 Name of young person Date Signature

.....
 Name of person taking consent (if different from researcher) Date Signature

.....
 Name of researcher Date Signature

Appendix 6- Consent Form for Young People (NHS version)

CONSENT FORM

Title of Project: An interpretative phenomenological analysis of young people’s experiences of living with a parent with mental health difficulties.

Researcher: Cassie Bromley, Trainee Clinical Psychologist

Please tick box

- 1) I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information and if needed ask questions that were satisfactorily answered.

- 2) I understand that participation is voluntary and I am free to withdraw at any time, without giving any reason, without healthcare or legal rights being affected.

- 3) I agree to take part in the above study

- 4) I agree for the interview to be audio-recorded

.....
Name of young person Date Signature

.....
Name of person taking consent (if different from researcher) Date Signature

.....
Name of researcher Date Signature

Appendix 7- Consent Form for Parents/ Carers (Voluntary Organisations version)



CONSENT FORM

Title of Project: An interpretative phenomenological analysis of young people’s experiences of living with a parent with mental health difficulties.

Researcher: Cassie Bromley, Trainee Clinical Psychologist

Please tick box

- 1) I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information and if needed ask questions that were satisfactorily answered.

- 2) I understand that participation is voluntary and that my son/daughter is free to withdraw at any time, without giving any reason, without healthcare or legal rights being affected.

- 3) I agree for my son/daughter to take part in the above study

- 4) I agree for the interview my son/daughter takes part in to be audio-recorded

.....
Name of parent of participant Date Signature

.....
Name of person taking consent (if different from researcher) Date Signature

.....
Name of researcher Date Signature

Appendix 7- Consent Form for Parents/ Carers (NHS version)

East London and The City **NHS**

Mental Health NHS Trust

CONSENT FORM

Title of Project: An interpretative phenomenological analysis of young people's experiences of living with a parent with mental health difficulties.

Researcher: Cassie Bromley, Trainee Clinical Psychologist

Please tick box

- 1) I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information and if needed ask questions that were satisfactorily answered.

- 2) I understand that participation is voluntary and that my son/daughter is free to withdraw at any time, without giving any reason, without healthcare or legal rights being affected.

- 3) I agree for my son/daughter to take part in the above study

- 4) I agree for the interview my son/daughter takes part in to be audio-recorded

.....
Name of parent of participant Date Signature

.....
Name of person taking consent (if different from researcher) Date Signature

.....
Name of researcher Date Signature

Appendix 8- Interview Schedule

Understanding of parents' mental health difficulties

When did you first become aware of their difficulties?

What did you think was happening?

How has your understanding changed over time?

How did you come to have this understanding? (Prompt: What influences i.e. reading, knowing someone going through similar, talking to someone?)

Do you have any unanswered questions about your parent's difficulties/ what would you like to know about your parents difficulties? (Prompt: Anything you wanted to ask but didn't? Any contradictions in what you've heard?)

Impact of difficulties

In what way do your parent's difficulties affect your life?

Can you give (recent) examples?

What impact do your parents' difficulties have on you? Tell me about a situation in which your parents' difficulties have had an impact on you?

- School
- Home
- Friends
- Family

Has anything positive come from your parent's having difficulties? (Prompt same areas: school, home, family, friends).

Coping and resilience

What is the hardest part of your parent's mental health difficulties for you? At first? Now? (Track change over time).

What do/did you do (to cope) when.....

- Who helps?
- Activities?
- Personal resources? Anything you think or tell yourself that helps you cope?

Has anything good happened as a result of your parent's difficulties in your relationships/activities/personal resources?

If your parent didn't have any mental health difficulties what would you lose/ miss?

What would have been different if your parents didn't have any difficulties?

- Relationships?
- Life style/ routine?

What have you learnt about yourself that you would not have otherwise known?

- What does this tell me about what you want for your life?
- Your values?

Services

What would you want from services if they were available?

- What would be helpful/ unhelpful?

Ending

Is there anything else you that is important for me to know about to understand your experience?

How has it been talking with me today?

Appendix 9- Interviewer Response Sheet

Reflections on the interview

Content

- What were the key themes and issues?
- Any evident conflicts/ dilemmas?
- Were there any unexpected themes?
- Were there any issues I should/ could have followed up in more detail? If so, why did I not do this?

Process

- Good rapport?
- Interviewee relaxed/ tense/ talkative?
- Any non-verbal feedback from interviewee?
- Anything else that might have influenced interview? E.g. interruptions or conditions in the room?

Reflections on interviewer performance

- Relaxed style? Subtle shifts of topic?
- All topics adequately covered?
- Was questioning style open enough? Any closed questions?
- Questions clear? Any indication of confusion from interviewee?

Initial ideas about links with theory/ literature

What can I take to the next interview?

Appendix 10- Audit trail

Chronological list of themes from the interview

Awareness	Mother meeting young person's needs
Shared identity/ similarity/ connection	Open communication
Uncertainty	Desire to understand
Support	Fluctuation in mother's response
Making sense	Bond v conflict
Passing it on	Talking openly helps
Others responsible	Connection v isolation
Struggle to make sense	Indirect communication
Protective/ caring role	Mother fulfilling her role
Difficult to talk about problems	Restriction
Talking helps	Loss (own difficulties)
Scared	Normal v Different
Difficulties unpredictable	Others not understanding
Conflict/ disconnection	Mother as protective
Frustration	Responding to mother's needs
Anger	Acceptance v questioning
Beliefs about difficulties	Loyalty
'Normal' appearance	Valuing mother
Responsible/ protective/ caring role	Reciprocal roles
Relationship difficulties	Interdependence
Emotional mirroring	Anxiety and relationship intertwined
Reciprocal roles- wanting to give back	Mother responsible for young person's anxiety
Different to others	Coping
Trying to make sense	Shared experience
Doesn't understand	
Person responsible for anxiety	
Knowing	

Appendix 10- Audit trail

Themes clustered

Trying to understand parent's mental health difficulties		
Awareness of parent's difficulties	3.15*	My Dad kind of gets nervous, but not really... just probably the amount as everyone, but my Mum gets like panic attacks. Or she has an anxiety disorder.
	4.31	I remember one time she got nervous in front of me ...
	5.10	We were on like a 393 I think, and we were going to [...] to the cinema. And um she was like starting to kind of look upset or nervous, but I didn't really understand...
	9.11	She'll kind of just look quite upset or distraught, like quite just worried. You can kind of tell if someone's worried.
	10.1	My Mum was just quite she... she looked... I was like, "Mum, what's wrong?" And she was like, "I just feel a bit nervous." ...
	12.28	I can't really remember how I came about to know about it, I just know that I do know about it.
Making sense: 'If she didn't have it, then I wouldn't have it'.	4.24	I think she kind of got it 'cause of her Dad. 'Cause when she was like 6 her Dad died in a train crash so she... she saw her Mum going all nervous over that, so then she started to develop anxiety. And then from her, I think I got it.
	5.24	And then years later when I started to get panic attacks she explained that she got panic attacks...
	11.2	I know I was thinking about my Mum, and then I thought, "Well I've never really seen her get nervous," then I was like, "Oh wait, I have." ...
	11.16	I'd say it's just when you get quite panicky and anxious, and sometimes you get yourself into a state where...
	11.28	They were just like, it's just when you get yourself into a state and you have to work yourself out of that state. Just as you've worked yourself in.
	17.9	People telling me that I might get nervous kind of made me nervous.
	17.22	My Mum was just like to my Dad, "Yeah I think... I think she's got my problem, I think she's got anxiety." And I didn't really know what anxiety was...
	18.29	Just anxiety is the kind of thing if I... if I say to myself, "I'm going to feel nervous, I'm going to feel nervous," I will feel nervous...
	30.8	I don't really think it's coincidental that her Mum had it, my Mum had it, and now I have it...
	33.12	And I really... I think if my Mum didn't have it then I probably wouldn't.
Struggle to make sense	5.1	I wasn't really aware of... at the time I wasn't really aware that she had like ... what it was. Like I didn't really... like I knew she was upset. I didn't really understand it...
	6.1	I was kind of worried 'cause I didn't really know what was going on, I didn't understand why she was so upset or why she was so distressed...
	8.27	Well I didn't really... 'cause again I was little at the time, I kind of thought, well I don't know, I don't know why, I just kind of thought, "Adults don't get nervous," ...
	11.9	Well a lot of people have explained it to me, um told me, you know, what's... how... what it's about and how it works. But I don't yeah in... in a way I still don't really understand it, but a lot more than I did before.
	13.20	I don't really understand it. I don't understand how something in my mind affects my body so much...
Communication fluctuates		
Difficult to talk about problems	5.21	I... I didn't really talk about it after that.
	15.25	I didn't really wanna ask her about it before. I kind of... I dunno why, I just kind of felt like it was an awkward... or I didn't... I felt really uncomfortable...
	19.30	I'm sure they'd be lovely about it, but I don't really know them well enough to feel that comfortable around them
	31.27	I just kind of make, you know, I suppose I really have to be in the position to explain what happens, 'cause it's different every time.
Talking openly helps	13.14	She tells me everything I want to know.
	14.16	Oh just asked like, "Why did you get it?" and, "How did you cope with it?" ...
	16.4	We had a proper chat about it, she was just explaining to me how it first came about...
	16.26	Well at first I... I just thought, well I kind of felt like, "Right well I should just go for it. If she doesn't want to speak about it then, that's it..."
Danger of discovering problems indirectly	17.17	It was more overhearing my parents talking about it, you know, "I think she's got anxiety," or whatever, or hearing my Mum on the phone to doctors.
	17.22	My Mum was just like to my Dad, "Yeah I think... I think she's got my problem, I think she's got anxiety." And I didn't really know what anxiety was. (...) at first I'd think of it as some sort of disease and like, "Oh no I'm dying." ...
	18.7	And I mean I was kinda in the hallway and they were in the kitchen. And I was just like [pause] "Oh God," and then I just went to bed 'cause I heard them coming. Yeah I... I just felt, "What's anxiety?" you know. I just kinda lay there thinking about it for a bit, and then I went to sleep.
Reciprocal roles 'caring to cared for'		
Adopting a protective, responsible, caring role	6.7	I was like, "Mum, it's fine, let's just go home, yeah." ... 216
	9.17	I say, "Mum, are you alright?" you know, whatever situation we're in. 'Cause it's not usually at home. So it's like, "Do you just... do you wanna get off the bus or whatever?"
	10.9	I was like, "Mum, are you alright?" you know, whatever situation we're in. 'Cause it's not usually at home. So it's like, "Do you just... do you wanna get off the bus or whatever?"

Shared difficulties cause conflict and disconnection between young person and parent	6.27	Usually we have arguments about it 'cause I... I miss a lot of class because of it. So that's how we talk about it, so we argue a lot. And sometimes obviously when I go like that she doesn't understand, but then again I know that she does understand.
	7.9	Because well she... um it's like what classes I'm going to, and if I miss one then she gets angry and then, you know, we start to argue about it.
	7.23	Well it really depends like how I'm feeling. Sometimes I'll be like, "I know, I know," and then I'll just get upset. But um sometimes I'll just get angry and be like, "Well you know what," and we... we start shouting, yeah, and it gets into quite bad arguments 'cause we're both like really angry.
	9.23	We were going to her... a doctor that she went to see about mine and her relationship, and how we argue.
	14.22	Um well when it's just me and her chatting and, you know, we're getting on, it's been quite nice 'cause I feel like there's somebody else there who understands it. But then when it's... when it's not me and her, or when we're having an argument, then it's not really a nice...
	24.21	A lot of the time I don't really feel like I can talk to like my mum.
Being different to others	10.17	Hardly any people get this problem, or that I've met, or children, so it's really weird seeing that happen.
	16.11	I got quite like emotional about it, because it was so weird to hear somebody saying something that I felt only I... I thought only I felt like...
	20.23	A lot of the time we got the train to places where other people would be like, "You get the train? I... I... I just drive."
	21.9	It was like, "Yeah I'm flying to [.]," and she was like, "Oh we just drive on the ferry." And a lot of my friends were like, "Yeah, yeah we just go on the ferry, we just drive." And I was like, "That's really weird." But it was weird to me (...) I'd just fly, that's just what I've been doing, you know.
	21.19	Well I just kind of thought, you know, they're the weirdoes not me.
	31.19	I draw attention to myself down the corridor 'cause people are like, "Why are you standing here?"
Loss and restriction	19.26	But it means that I can't ...like with the boys, I don't really wanna go places like with just them and me.
	20.7	Well it's alright 'cause usually it's not just me and the boys, so I suppose it's not that much of a loss.
	23.21	Which is weird because I'm like, "Well I want to go see [.]," but, "You can't do it 'cause I'm nervous."
	33.17	It affects a lot of aspects, like there are a lot of things I can't do.'
	33.21	Like I can't get on a bus and go to Oxford Street by myself. I know the way, and I know how to get there, but I can't do it.
	Resilience/ coping	
Managing but unsure how	27.10	I... I don't really do anything. I just do cope with it and do manage it.
	27.21	I usually just you know, shout and just go 'grrrr' and then just kind of ... and lie on the bed and listen to music or something.
	28.14	When I'm nervous I just say, "You're fine. Nothing's going to happen to you, you're fine."
		Not really much of a difference, I just do it instinctively I suppose.
	28.20 30.28	I don't really think I've learnt anything so far, but I think I will learn how to cope with it better.

*= page number: line number

Appendix 11- Example of letter to sent a young person inviting feedback



Cassie Bromley
Doctorate in Clinical Psychology
Health and Human Sciences Building
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

Name
Address
Address
Address

13th May 2008

Dear ...,

Research Project: Young people's experiences of living with a parent with mental health difficulties

Thank you for taking part in the research project. It was great to meet with you and talk to you about your experience of living with your mum.

As I explained when I met with you, I would like to share my analysis of the interview and offer you the chance to give some feedback. I have enclosed a write up of the interview and a summary of the main themes I found in the interview. Also enclosed is a feedback sheet and stamped addressed envelope to return the feedback in. I would be grateful if you could look at the summary of themes and let me know what you think about them. Any ideas are welcome; it does not matter if they are different to mine, I am really interested in what you think. To ensure I can include your feedback in the research could you please return the feedback sheet to me by the **30th May 2008**.

I will write to you again with a summary of the overall results of the research when it is completed. If you have any questions please get in touch at the above address, by phone (University: 01707 286322) or email (c.bromley@herts.ac.uk).

Thanks again for taking part.

Best wishes,

Cassie Bromley

Main themes from the interview

Trying to understand mum's anxiety

You were aware of your mum's anxiety and spoke of being able to tell when she becomes worried. You had struggled to make sense of your mum being upset and nervous at first as you did not know what was going on. You said this had made you feel scared. Whilst you have had a lot of people explain to you about anxiety and how it works you still feel you do not really understand it. You said you struggle to understand how something in your mind affects your body so much, or why it happens when it does.

You have made sense of your mum's nervousness by linking it to your grandma's nervousness, which started after your grandfather died. You felt quite strongly that your nervousness was linked to your mum's nervousness and that it was either something genetic or something going around in your family. You had heard you parents talking about you having anxiety and felt their expectation that you might get nervous had made you nervous.

Communication fluctuating

You indicated that talking about anxiety with other people is difficult. You said at first it had been difficult to talk to your mum about her anxiety as you felt awkward and uncomfortable asking her questions. You spoke of having felt scared talking about it because it had never really been spoken about. However it seemed that talking openly about anxiety was helpful to you. You explained that when you decided to talk to your mum about her anxiety she had answered all your questions and had a proper chat with you about it. One of the dangers of not talking openly seemed to be that you discovered things indirectly. You spoke of how you had overheard your parents talking about their worry that you had anxiety. You did not know what this meant as your mum's difficulties had not been spoken about in the family at that point and you were left to make of sense of it by yourself. At first you thought anxiety was a disease and that you might be dying and then over time you figured it out.

Caring and being cared for

You seemed to be caring towards your mum when she became anxious. You spoke of reassuring your mum and checking how she feels if she seems anxious. You also spoke of your desire to comfort and help your mum when she becomes nervous because she has often comforted you when you have felt nervous. You seemed aware of your mum's needs and tried to respond to them. For example because of her worry about the family getting sick, you waited to visit your friend until she was better after being ill. Although you felt helping your mum in this way was at odds with what she told you about doing things even if you're nervous of them.

It also seemed you felt cared for by your mum. You said your mum did not seem nervous and rarely became nervous. You spoke of your mum getting on and doing what she needed to and her nervousness not being obvious. You saw your mum as coping with her anxiety and did not think it affected the good times you spent together. You said your mum was like your friend and that you would have nice chats, go shopping and laugh together. You spoke of feeling as if you could tell her a lot of things and it appeared you valued this part of your relationship.

Anxiety divides and connects people

You spoke of a lot of similarities and connections between you and your mum. You talked about how you were both angry people, who shout and have arguments and how your relationship together is quite fiery. You also spoke about how you both felt nervous at times and shared the problem of anxiety. The support you received from your friends, teachers and CAMHS because of your anxiety seemed to help you feel connected to and cared for by others.

Anxiety seemed to cause conflict and arguments between you and your mum. You said the arguments often occurred when you missed school. Although you expected her to understand about your anxiety because of her experience, you said sometimes it seemed as if she did not because of the way she reacted towards you. Whilst there were times you felt you were able to chat with her about it and she understood, at other times you felt she did not support you and told you to find your own way to cope. You spoke about this pissing you off, causing big fights and leaving you feeling as if a lot of the time you could not talk to your mum.

The anxiety appeared to make you feel different to other people. You spoke about how hardly anyone else experienced the problem and that talking to other people who did experience it made you feel less alone. You also talked about how anxiety means you miss a lot of classes and are not able to do some things others can, which draws attention to yourself.

Coping

You spoke of dealing with and managing your anxiety although you were not sure how you did. You were not aware of any particular helpful coping strategies you used, although spoke of doing some things instinctively such as reassuring yourself nothing would happen and things would be okay. You also said you slept or listened to music to manage difficult feelings.

A JOURNAL READY COPY OF A REPORT OF RESEARCH

‘She born me and I need to take care of her’: The experiences of adolescents living with parents with mental health difficulties

Cassie Bromley

June 2008

Year 3

Word count: 5,078

‘She born me and I need to take care of her’: The experiences of adolescents living with parents with mental health difficulties

Abstract

Despite much research in parental mental health, the experiences of young people whose parents have mental health problems have rarely been considered. This paper, focusing on this gap in understanding, presents the findings of an Interpretative Phenomenological Analysis of interviews with seven adolescents about their experiences of living with parental mental health difficulties. The results suggest that young people often experience uncertainty when trying to make sense of their parent’s difficulties, finding it hard to talk about them. Their relationships with their parents appear complex, with simultaneous experiences of feeling cared for and isolated integrated alongside a desire to look after their parents and, sometimes, frustration at their parent’s difficulties. These experiences seem to foster strong bonds between parents and young people, with some emotional mirroring apparent. Consistent support and adaptive coping are identified as important resources in the young people’s experience. These findings are considered in relation to existing literature and the clinical implications are outlined.

Introduction

Over fifty years of research into parental mental health problems has provided little insight into the experiences of their children beyond highlighting increased risk of developing their own difficulties (Bromley, 2007). The risk narrative has been dominant since Rutter and Quinton’s seminal research (1984) indicating a third of children whose parents have mental health problems develop persistent psychological problems, compared to one sixth of controls. The risk of harm has also been highlighted in child protection literature, with child welfare concerns linked to parental mental health in a quarter of child protection conferences (Farmer & Owen, 1995). The negative effects of parental mental health are suggested to be mediated in various ways, including the direct effects of parent symptoms, the effect on a parent’s capacity to relate to and parent their child, associated alterations in family structure or functioning and associated risk factors (Falkov, 1998). Alongside this risk dominated research is the less apparent message that social factors such as aggression,

marital discord, unemployment and poverty have a greater influence on the risk to these children (Hall, 2004) and that many do not develop difficulties (Falkov, 1998). This highlights the danger of dominant narratives, which become problematic when they constrain us from noticing experiences that might be quite useful (Madsen, 2007).

Shifting to a focus on competence

With mental health services organised around problems and disorders, conversations in services tend to be problem-saturated, with scant attention paid to families' strengths (Carr, 2006). Experiences demonstrating positive aspects often go unstoried and valuable resources unnoticed (White & Epston, 1990). In parental mental health research, risk focused research dominates and only one study highlights the positive aspects of parental mental health problems for children (Aldridge & Becker, 2003). Aldridge and Becker's research (2003) demonstrates that parents with mental health problems can have strong and effective relationships with their children, enduring even when difficulties persist. Moreover, they highlight that the role adaptations children make sometimes cement parent child relationships rather than adversely affect them and parents try to compensate for 'bad' times when their mental health improves. A positive approach increases learning about how to prevent difficulties occurring and how to build qualities that help families not just survive, but also flourish (Seligman, 2005). Taking such an approach does not prevent consideration of risk issues or child protection, nor does it minimise the negative experiences of some children; instead it widens the scope of what is heard and broadens understanding. Hence, redressing the research balance with a focus on positive factors associated with parental mental health problems and processes associated with resilience is encouraged (Cogan *et al.*, 2005; Gladstone *et al.*, 2006).

Employing a qualitative approach to re-search young people's experiences for alternative narratives

Historically research in parental mental health has mainly been quantitative and therefore unable to provide information about the richness and complexity of young people's experience, hence qualitative approaches are advocated (Mordoch & Hall, 2002; Leverton, 2003). Moreover, many have highlighted the lack of inclusion of young people in this research (Gladstone *et al.*, 2006, Leverton, 2003; Mordoch & Hall, 2002). Encouragingly, some international research has begun to address this, with qualitative studies involving

young people now emerging (Garley *et al.*, 1997; Fudge & Mason, 2004; Maybery *et al.*, 2005; Handley *et al.*, 2001; Meadus & Johnson, 2000; Riebschleger, 2004; Polkki *et al.*, 2004). In the UK a handful of studies, drawing predominantly on young carer samples, have been published (Webster, 1992; Armstrong, 2003; Aldridge & Becker, 2003; Stallard *et al.*, 2004). Common themes arising from these include young people's lack of understanding about their parent's problems, anxiety about their parent's and their own mental health and experiences of economic disadvantage and isolation. The benefit of using qualitative approaches to explore young people's perspectives is the potential to gain real insight into their experiences as their accounts have greater validity than third person accounts offered by researchers and professionals.

Barriers to entering into research conversations with adolescents

One difficulty encountered when trying to explore young people's experiences of parental mental health problems is they are a relatively 'hidden and invisible' population (Riebschleger, 2004; Elliot, 1992). Services' failure to recognise when children are present or consider their needs is well documented (Howard, 2000). With data rarely collected on whether adults accessing mental health services have children (Falkov, 1998), accessing this population is not straightforward; researchers attempting to do so often comment on the difficulties (Handley *et al.*, 2001; Aldridge & Becker, 2003; Stallard *et al.*, 2004). Issues of stigma, parental fear of acknowledging an impact on their children, or having them taken into care are highlighted as some of the barriers (Aldridge & Becker, 2003; Handley *et al.*, 2001; Stallard *et al.*, 2004). Similarly, children's reluctance has been hypothesised as protective; with some perhaps anticipating negative consequences from discussing their parent's difficulties (Stallard *et al.*, 2004). Service factors have also been recognised, such as resource limitations, a traditional client-focused approach in adult mental health leaving little time for consideration of child needs and a wish to protect adult clients from feeling under scrutiny (Stallard *et al.*, 2004). Thus the perception of the topic as sensitive or threatening is seen as presenting a substantial challenge to recruitment (Cogan *et al.*, 2005).

Research aims

Research in parental mental health has been constricted by a dominant risk orientated narrative. Through consideration of the benefits of taking a positive psychology approach

(Seligman, 2005) and a focus on competence, the need to widen the research scope is evident. The objectives of this study were to explore adolescent experiences of living with parental mental health problems using a qualitative approach. To offer an alternative narrative to the negative one dominant, the aim was to develop a rich descriptive and interpretive account, paying attention to the complexity and context of adolescent experiences.

The main research question was:

- How do adolescents experience their parent's mental health problems?

Method

Ethical approval for the study was granted by the University of Hertfordshire for the recruitment of participants from voluntary organisations and by Hounslow and Hillingdon NHS Research Ethics Committee for the recruitment of participants through the NHS.

Participants

Young people were recruited through two CAMHS teams, a Parental Mental Health Support Project and Young Carers Project. In total 22 young people were invited to take part, seven of whom agreed. Of those participating two were male and five were female, two were twins. Aged 13 to 15, they were from a diverse range of ethnic backgrounds. All had mothers with longstanding mental health difficulties, such as depression and anxiety.

Data collection

Semi-structured interviews were carried out using an interview schedule, designed to facilitate conversation about the young people's experiences. The main areas enquired about were:

- 1 Understanding of their parent's difficulties
- 2 The impact on their lives
- 3 Their relationship with their parent
- 4 Their coping strategies and resources

Four young people chose to be interviewed at home and three at the Young Carers Project. The twins chose to be interviewed together.

Data analysis

Interpretative Phenomenological Analysis (IPA) was used to analyse the transcripts, as detailed by Smith (Smith, 1996; Smith & Osborn, 2003; 2008). The process was also informed by guidelines for ensuring quality in qualitative research (Spencer *et al.*, 2003; Elliot *et al.*, 1999; Yardley, 2008) and through supervision from an experienced IPA researcher. In line with IPA's idiographic approach each transcript was looked at in detail individually before they were considered together.

Results

This account should be viewed as socially constructed, partial and incomplete in line with the study's underlying theoretical orientation (Smith & Osborn, 2008).

Trying to make sense in uncertainty

Young people seemed to become aware of their parent's mental health difficulties through witnessing behavioural changes. This appeared to allow them to gauge the intensity of their parent's difficulties, as Alara describes.

When they first got divorced my Mum was really upset and she used to take a lot of tablets and everything (...) like she used to always cry. (Alara)

The extent to which they acknowledged their parent's difficulties appeared embedded in their construction of differences and 'normality' within the family. The role of representations of mental health problems appeared important, with the everyday reality of parental mental health difficulties seemingly at odds with cultural stereotypes. For some the tension between acknowledging differences and describing 'normality' seemed born out of a desire not to be stigmatised or seen as different. The desire to be 'normal' was articulated by Emily.

'Cos sometimes I'm kind of like I'll just wonder, like why can't she just be normal? Like it's kind of annoying. Kind of like, oh ... why can't she just... like all the other parents... all the other children, they don't know that ... they're like they take their parents for granted. 'Cos they're just like normal.
(Emily)

A striking element in the young people's experiences was the uncertainty that seemed to envelop their parent's difficulties. This appeared to derive partly from seeing their parent's were experiencing difficulties, but not knowing what they were or why. Some clearly experienced strong emotions when faced with uncertainty, feeling scared not knowing what was happening. These feelings seemed most prominent when first discovering their parent's difficulties, with the shock of their parent's distress unsettling. Katie's reaction demonstrates how being aware of something without understanding can lead to feeling unsafe.

I was kind of worried 'cos I didn't really know what was going on, I didn't understand why she was so upset or why she was so distressed. So I was kind of scared. (Katie)

To manage this feeling they attempted to make meaning and develop explanations for their parent's behaviour. However, this process also seemed fraught with uncertainty for some; feeling unsure about the reasons behind their parent's difficulties made it hard to make sense of what they observed. The apparent incomprehensibility of parental difficulties is captured by Alara talking about her mum.

'Cos she gets upset sometimes for many reasons, not sure why (Alara).

Often young people sought to make sense by looking to the familiar, connecting their parent's difficulties to external factors or events. Relationship difficulties, parental separation, physical and environmental factors provided concrete explanations for their observations. Anna sought to explain her mum's difficulties by environmental reasons.

I think it's the housing, she don't feel comfortable here, like it's a very small place and like that's it. (...) It's the area and like lack of space, because like for instance, not sure, I don't know. (Anna)

The degree to which some remained tentative was notable; indicating a sense of uncertainty remained. Whilst many tended to hold a simple single explanation for their parent's difficulties, some tried to develop a more complex understanding. Katie attempted to hold multiple explanations for her and her mum's anxiety, incorporating ideas of genetics and systemic factors, looking beyond the familiar.

I don't really think it's coincidental that her Mum had it, my Mum had it, and now I have it. It's obviously something genetic, or something going round in our family. So therefore I think if she didn't have it, then I wouldn't have it.
(Katie)

Appearing to find it difficult to integrate these ideas, she wished to know how the explanations translated to the difficulties she observed. Her struggle to understand how mental health difficulties occur was prominent, even with repeated explanations, a satisfactory understanding remained elusive.

Well a lot of people have explained it to me, told me, you know, what it's about and how it works. But I don't, in a way, I still don't really understand it.
(Katie)

Talking: good in theory, hard in practice

There were mixed feelings about talking about parental mental health difficulties. Some directly expressed their reluctance to talk with friends and parents.

Sometimes you don't always wanna talk. Like I know people say you should like let it out, but sometimes that's not always what you wanna do. (Hayley)

It also became apparent during interviews that some had difficulty talking, struggling to articulate their experience.

I'm not sure, I don't know she doesn't like show, how can I explain it, it's just I know, like she'll say sometimes like, oh I'm not sure, I don't know, I don't how to explain it. (Anna)

Finding it hard to talk seemed related to concern for how others might react and a wish to avoid thinking about what was difficult or uncertain. The difficulty broaching the topic with parents was also articulated.

I felt really uncomfortable asking her about it. Because it was one thing we didn't really talk... we talked about my anxiety, but we never really talked about her life, or her anxiety. So when I asked her, at first I was a bit scared. (Katie)

Parents' limited talk about their difficulties seemingly hindered the young people talking. When attempting to describe their parent's difficulties some referred to their parent's silence on the subject.

Not quite sure actually 'cos she doesn't talk about it that much. (Alara)

The majority of communication about parental mental health difficulties within families seemed indirect, with young people overhearing things rather than being told directly.

It's kind of seeing it. And like my Grandma's always like (...) "You have to eat because... unless you're just gonna start your fit again. So just eat and take your tablet." So it's like kind of hearing about it as well. (Emily)

The potential danger in gathering information indirectly was highlighted by Katie who described her catastrophic sense making when overhearing her parents talking. Without the opportunity to check out her sense making she coped independently with her conclusions.

My Mum was just like to my Dad, "Yeah I think she's got my problem, I think she's got anxiety." And I didn't really know what anxiety was. (...) And I thought... at first I'd think of it as some sort of disease and like, "Oh no I'm dying." (Katie)

Alongside reluctance to talk, some expected talking would be helpful, informed by professional discourses that letting things out helps. Chris spoke of wanting talking therapy following his mother's death and the onset of his aunt's mental health difficulties.

Yeah we just wanted to talk about it. Like sometimes you see them on the television, and you know like you're supposed to talk. And just say your thoughts, and they give you some advice, and you might listen to it come back and they'll see how you are after that. (Chris)

The benefits of talking within the family about parental problems were also evident. Katie's experience of talking with her mum about anxiety shows that talking openly can be helpful.

I kind of felt like, "Right well I should just go for it. If she doesn't want to speak about it then, that's it, she's your Mum, she's one person, you know, you really shouldn't feel embarrassed to talk to," so I, you know, I just went for it. And she did answer me. And then after that I kind of felt comfortable about it. (Katie)

Reciprocity and connection v frustration and disconnection

A prominent theme that emerged was the protective, caring and responsible roles the young people adopted towards their families. There seemed to be a desire to look after their family and ease parental difficulties, illustrating the strong bonds and reciprocity between young people and parents.

She's my mum and she born me and then I need to take care of her. (Emir)

This desire to care was demonstrated in a variety of ways, some did household chores, some reassured their siblings, some their parents and some tried to minimise their parent's stress by behaving well. It was apparent that some assumed responsibility for their parent's wellbeing, considering their needs and helping them when upset.

Sometimes I'm like worried to leave her alone, at home when I'm going to school, (...) even like when I went to school I used to always think about her. (Alara)

At times the sacrifices made as a consequence of placing their parent's needs before their own were experienced as annoying.

It's not always good though, 'cos we have to collect our little brother [from school] (...). It's annoying. (...) When you've got something planned like (...) you've gotta cancel it. (Hayley)

Thus the desire to care was juxtaposed with some feeling frustrated and restricted by their parent's difficulties, demonstrating the complexity of the connection between young people and their parents, and the integration of opposing views.

Also salient was the young people's experience of feeling cared for and looked after by their parents. It appeared that, in spite of mental health difficulties, parents showed resilience by continuing to meet their children's needs. The warmth and affection for their parents was clear when they talked about what they valued about their relationships. Amongst their descriptions was the sense their parents were doing their best trying to maintain a familiar routine. For the young people parents showing interest in their development and providing boundaries symbolised caring.

She acts like our Mum and stuff, like we have to ask for stuff, we have to... say when she tells to come back home like, she isn't just like one of those parents that say, "Oh yeah you can do whatever you want." (Chris)

It was apparent that, even though all felt parented and cared for, some had simultaneous experiences of their parents being unavailable, producing feelings of isolation.

She used to be miserable all the time, and she didn't want no one to come and see her (...) she wanted to stay alone from everyone and she was always sleeping and taking sleeping pills and sleeping, and I got really upset 'cos I felt alone. (Alara)

The young people seemed to manage the fluctuation in parent availability by perceiving the good times as fragile and more valuable, which further strengthened the bond with their parents. The connection and reciprocity between them was also seen in their description of their feelings. For some their emotions mirrored their parents, as they responded to their parent's emotional states with similar emotions. This partly seemed connected to concern about what might happen when their parents were distressed; with the young people perhaps aware of the impact of their parent's distress, they too became upset and worried.

When she starts crying and she can't control her breathing. Yeah and then I get upset as well. (Alara)

Some emotions seemed to be felt on their parent's behalf; the strength of their bond leading the young people to attempt to shoulder some of their parent's difficult feelings. Some directly connected their happiness to their parent's, predicting they would be happy if their parent no longer experienced mental health problems. This again highlighted the connection between parents and young people, but also the dependence of their feelings on things beyond their control.

I don't know, I feel... like she's happy I'll be. (Anna)

Positive resources and adaptive coping

Consistent support from family, friends and services was valued by the young people. It allowed them to feel accepted and not alone and provided some relief from feeling responsible for their parents. Some described how family members stepped in to support them. Emily's grandmother provided Emily with a secure and consistent attachment.

[Mum and I] like we're close, but not as close as my Grandma. (...) My Grandma was always at home, so she was the one that really looked after me, if I think about it. (Emily)

Feeling there was someone there for them when needed appeared central; with a sense of belonging seemingly underlying positive experiences of support. In contrast some young people identified when support did not go far enough, this seemed linked to a lack of

continuity. Efforts to help which were brief or only related to times of crises were not seen as good enough.

She's had a few counsellors and stuff, and they haven't really helped because she's getting one after another, and right now she doesn't have one. So I don't think they're helping. (Hayley)

A positive view of self-sufficiency was particularly compelling in the experiences of those accessing Young Carer's. Viewing their independence and ability to look after themselves as advantageous, taking responsibility for themselves was normalised for them, as demonstrated by their reaction to discovering others did not have their skills.

Well you don't actually realise that you've learnt it, it's just like the only time that you realise is when you hear someone saying like, "I don't know how to wash my own clothes," or... I've got some friends that their Mum cleans their room, does their clothes, makes them breakfast and whatever. (...) When they live out they're not gonna have those skills for themselves. (Hayley)

The young people appeared to have learnt their own ways of managing difficult emotions, their resilience evident from the adaptive strategies they developed. Amongst the cognitive coping strategies used were acceptance of difficult thoughts and situations. This seemed a positive and adaptive approach to managing, allowing them to move on and do what they wanted.

It's just like little [worry] thoughts, it's not like a long thought (...) just little thoughts when it does happen. (...) I kind of... it's not as if I push it to the side, but I'm just like, "Oh whatever," and just kind of do whatever, and I'll sort of do it. (Emily)

Like you're feeling like you're forgiving yourself for blaming yourself ... or something like that. So you kinda it's releasing all the grief. So you don't feel that way anymore, kind of. (...) It makes you feel more... kinda more because you've realised that you can lift up the sadness so you can get on with stuff. That's like the easiest way to do... it's not really a technique. (Chris)

Distraction was used by many to cope with difficult feelings in relation to parental mental health difficulties; the need to escape apparent in Emir's words.

Sometimes, sometimes I try and take it out my head and do something else.

(Emir)

Amongst the activities young people engaged in to distract themselves were playing, listening to music and sleeping. The benefits of distraction seemed linked to their wish to contain difficult thoughts and avoid getting into a negative cycle of escalating difficult feelings.

Discussion

The study's findings were broadly consistent with the literature and expand understanding about young people's experience of parental mental health problems. Developing awareness through witnessing behavioural changes and overhearing conversations is consistent with research highlighting the importance of experiential knowledge (Totsuka, 2008) and observation (Cogan *et al.*, 2004; Riebschleger, 2004; Garley *et al.*, 1997). Similarly the study supports research finding that uncertainty and confusion are experienced by young people in relation to their parent's difficulties (Meadus & Johnson, 2000; Handley *et al.*, 2001). However support was not found for the commonly reported view that, in uncertainty, there is a tendency for young people to develop false beliefs about their responsibility and blame (Kelly, 1999; Place *et al.*, 2002). Instead there seemed to be great diversity in young people's sense making, with it mainly involving external and contextual factors.

The finding that there were mixed views about talking about parental difficulties matches Stallard and colleagues' findings (2001) and demonstrates the complexity and contradictions about talking. Some viewed talking about their parent's difficulties positively, with young people finding talking helpful, enabling understanding and relief of difficult emotions. This offers support for Oppenheim's (2006) view that talking can help the development of coherent narratives which facilitate coping. The importance of support is emphasised repeatedly in the literature (Parrott *et al.*, 2008), the finding that consistency

is central to young people's positive experiences of support builds on current understanding and is useful when considering what may encourage young people to talk.

This study adds weight to the idea that caring seems reciprocal and a function of the strong bonds between parents and children (Aldridge & Becker, 2003), moving away from the idea of parentification (Garley *et al.*, 1997; Handley *et al.*, 2001). In line with factors suggested to promote resilience (Parrott *et al.*, 2008) young people experienced their parents as caring, available and supportive. Consistent with other research young people experienced feelings of isolation when parents were unavailable (Meadus & Johnson, 2000; Riebschleger, 2004). Yet, unlike much previous research, this study demonstrated the complexity of young people's experiences as they managed conflicting feelings, with some feeling isolated whilst simultaneously valuing the care and love from their parents.

Apparent protective factors corresponded to previous findings about young people's use of activities and distraction (Garley *et al.*, 1997; Fudge & Mason, 2004). Valuing self-sufficiency was also highlighted in addition to cognitive coping strategies, such as acceptance and cognitive defusion. Cognitive coping strategies have received limited attention in this area; hence this appears to be significant, adding to understanding about young people's experiences.

Implications for practice

As awareness of parental mental health problems can cause difficult feelings for some young people, supporting them to make sense of their parent's difficulties is important. Parents can play a crucial role in children's sense making and hence services should seek to help them support their children with this complex task. Paying attention to the context when supporting families to develop their own shared meaning for mental health difficulties is indicated; whilst remaining aware that professional explanations may not be helpful as young people reach diverse explanations, often including external factors. Encouraging families to have ongoing conversations about mental health may foster young people's communication about their parent's difficulties and help them overcome any uncertainty.

Developing a trusting relationship with young people might be necessary before they feel able to talk about their parent's difficulties; hence professionals should allow time for this

and consider exploring the barriers to talking. It may be helpful to approach the complex nature of relationships between parents with mental health difficulties and their children from a positive stance, perhaps using the frame of reciprocity as a starting point. Providing this context may free young people to view the whole of their experience, facilitating them to talk about difficult aspects and their strengths. This could then direct work towards strengthening their existing skills and resources with the aim of enhancing their coping.

Encouraging consistent sources of support for young people through family, friends and the community is potentially advantageous. Voluntary services can play a vital role having the potential to offer consistent long-term support. Statutory services could take a lead in supporting such services and an active role in increasing mental health awareness and acceptance. This task is of particular importance given the underlying theme of stigma surrounding parental mental health difficulties.

Methodological considerations

As IPA is an idiographic approach which does not seek to find definitive and positivist answers, it is not possible to generalise the findings to all young people living with parental mental health difficulties. Instead IPA aims to contribute to a gradually developing knowledge base, resonating with professional and personal experiences and shedding light on the broader context (Smith & Osborn, 2008). Thus, it is necessary to acknowledge that the findings provide an in-depth insight into the salient themes of the participants' experiences in this specific study (Smith & Osborn, 2003) and the findings' transferability must be considered within context. Young people who chose not to participate or who did not have contact with the services used for recruitment might have qualitatively different experiences of parental mental health problems to those participating. Hence the recruitment strategy needs consideration when contemplating the findings' transferability.

Recruitment difficulties encountered by other researchers were congruent with my experience. Understanding that many young people do not conceptualise their parent's mental health difficulties as such is crucial when carrying out research. This raises an interesting dilemma between transparency in research aims and making research meaningful to potential participants, highlighting the importance of language and the need for creativity to balance these issues. Moreover it warns of the potential disadvantages of

using professional conceptualisations and not matching understanding to the target population.

Future research

Further qualitative research could explore the experiences of young people at different developmental stages, from different social contexts and whose parents have different mental health difficulties or are at different stages in the course of them. In addition different strategies of recruitment could be used to target different populations of young people. Actively including young people whose fathers have mental health difficulties in future research is important, as living with paternal mental health difficulties may result in a qualitatively different experiences to maternal difficulties. This study did not specify which parent should have difficulties, but no young people whose fathers had difficulties participated; suggesting special emphasis is needed in this area.

Future research could consider how young people's experiences fit with other family members' perspectives. Taking a systemic perspective could help elucidate the relational processes within families where parental mental health difficulties are present, thus broadening knowledge about communication, parental relationships and family resources. Recognising the important role of attachment in child development, research could focus on how attachment relationships foster resilience in these families and how reciprocity and fluctuations in parent-child relationships influence resilience. Further emphasis on the resources and adaptive coping of young people, in particular cognitive coping strategies, may also give further insight into the resilience processes that occur in spite of mental health difficulties and help direct services as to how to enhance such processes.

Conclusion

This study offers a rich account of the experiences of adolescents living with parental mental health difficulties, highlighting the complexity of their relationships with their parents, the reciprocal nature of caring and the protective factors that can develop.

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